INTRODUCTION

The National Health Service has been described as Britain’s best loved institution.\(^1\) Tony Blair has claimed that is one of the country’s greatest achievements.\(^2\) It is not only of great national importance, but it is also the scene of huge political controversy and regularly appears at election times as one of the issues voters feel most strongly about.\(^3\) The World Health Organization has said it is one of the best in the world.\(^4\)

This chapter will be looking at the structure of the NHS and some of the key issues facing those dealing with its management.\(^5\) Although the structure of the NHS and the way the money allocated to the NHS is distributed and spent may not at first sight appear the most fascinating of topics, in fact there are a large number of important and interesting issues that are raised. To discuss properly the structures of the NHS and all the surrounding issues would take, at least, a substantial book in itself. This chapter therefore will briefly summarize the structure of this vast institution and then select some of the most topical issues facing it.

The first point to emphasize is that the NHS is, quite simply, enormous. Consider these statistics:

- In 2007–08 the total expenditure on the NHS was £90 billion. The Government has announced that this will increase to £110 billion by 2010–11.\(^6\)
- This is not to mention private health care where in 2005 the total spending among the general public exceeded £10,500 million.
- In 2006 there were 10.7 million people admitted to NHS hospitals. There are some 300 million consultations with a GP each year.\(^7\)
- The number of NHS prescriptions dispensed in 2006 was 834.4 million, or 13.9 items per head of population.\(^8\)
- In March 2006 there were 1,338,000 NHS staff.\(^9\)

In 2006 £1,982 was spent by the Government per person per year on the NHS.\textsuperscript{10} In 2006 UK health expenditure was 9.4 per cent of GDP, placing the UK in the mid range of OECD countries.\textsuperscript{11}

1 What are the principles underpinning the NHS?

The Government has set out the core principles underlying the NHS.\textsuperscript{12} These are:

(1) The NHS will provide a universal service for all based on clinical need, not ability to pay.
(2) The NHS will provide a comprehensive range of services.
(3) The NHS will shape its services around the needs and preferences of individual patients, their families, and their carers.
(4) The NHS will respond to the different needs of different populations.
(5) The NHS will work continuously to improve the quality of services and to minimise errors.
(6) The NHS will support and value its staff.
(7) Public funds for health care will be devoted solely to NHS patients.
(8) The NHS will work with others to ensure a seamless service for patients.
(9) The NHS will help to keep people healthy and work to reduce health inequalities.
(10) The NHS will respect the confidentiality of individual patients and provide open access to information about services, treatment, and performance.

In summarizing the modern NHS the Secretary of State for Health has described the service as:

An NHS which is fair to all of us and personal to each of us by offering everyone the same access to, and the power to choose from, a wide range of services of high quality, based on clinical need, not ability to pay.\textsuperscript{13}

The Chief Executive of the NHS, with a more open acknowledgement of financial reality, has stated its aims to be:

to promote health, reduce health inequalities, and deliver the best possible care for the population with the resources available.\textsuperscript{14}

In delivering these aims the NHS accepts that it is facing challenges. The Department of Health sees these as the major ones:

- Rising expectations: the NHS is delivering shorter waiting times and better services, but is still some way short of providing people with the control, choice, and convenience they expect in other parts of their lives.
- Demographics: an aging population, with increasing numbers of people with long-term conditions, requires the NHS, in partnership with local authorities and others,

\textsuperscript{10} Association of the British Pharmaceutical Industry (2007). Although the amount spent per person on particular services can vary enormously between primary care trusts (PCTs) (see King’s Fund (2006)).
\textsuperscript{11} Association of the British Pharmaceutical Industry (2007).
\textsuperscript{12} NHS (2007b).
\textsuperscript{13} DoH (2004a: 7).
\textsuperscript{14} DoH (2006b: 1).
to focus more on promoting good health, well-being and independence. This has implications for how services are organized.

- Changes in medical technology: these are transforming the ability of the NHS to prevent, cure, and manage disease, but are also creating new costs and a need to change the way services are configured.
- Variations in quality, safety, access, and value for money: in a national health service, people are rightly concerned about ongoing variations in the care on offer in different parts of the country.

To meet these challenges the Department of Health promises:

- more choice and voice for patients, giving patients real power, backed up by strong commissioning;
- more diverse providers, with more freedom to innovate and improve services, and more competition on quality;
- financial incentives to improve care and promote sound financial management and best value;
- national standards and regulation to guarantee quality, safety, and equity;
- sustained focus on information management and technology to underpin the reforms and deliver better, safer care.

2 The structure of the NHS

The structure of the NHS differs between England, Wales, Scotland, and Northern Ireland. This chapter will look only at England. To describe the structure of the NHS is not an easy task. Partly because it is labyrinthine, and partly because the NHS is undergoing enormous structural changes with bodies being created, merged, and destroyed at an astonishing rate. The structures of the NHS are undergoing these fundamental changes following an important Government Paper, *Shifting the Balance of Power*, which is designed to create a service centred around patients. The Government is also in the midst of rearranging the ‘arms length bodies’ which play a crucial role in the governance of the NHS.

At a basic level it is possible to examine the structure as consisting of four levels:

1. Policy making and centralized planning. This task is carried out primarily by the Department of Health.
2. Supervision, inspection, and regulation. This task is now often carried out by ‘arms length bodies’. These bodies are created by and are responsible to the Department of Health but are independent of it.
3. Service commissioners. These bodies decide which health services are ‘purchased’ and from whom. This is carried out by, for example, Primary Care Trusts (PCTs). They have the responsibility for assessing the health needs of people in their area and ensuring that their needs are appropriately met.

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15 See Wanlass (2006) for a detailed discussion of the health care needs of older people.
16 DoH (2006b: 5).
17 DoH (2006b: 5).
18 Webster (1998).
(4) Health care providers. These are those on the front line who are directly provide the health care to patients and include, for example, doctors and nurses.

We will now look at these different groups of bodies in more detail.

3 Policy and central planning in the NHS

3.1 Parliament

It is, of course, Parliament that approves the allocation of funds to the NHS via taxation. The Secretary of Health is accountable to Parliament for the performance of the NHS in England. There are also three Parliamentary Select Committees who can make inquiries and produce reports in relation to the NHS. These are:

- the Health Committee which examines the Department of Health’s expenditure, administration and policymaking;
- the Public Accounts Committee which ensures that the NHS is running economically, effectively, and efficiently;
- the Public Administration Committee which scrutinizes the Health Service Commissioner’s reports;

3.2 The Department of Health (DoH)

Under the Ministry of Health Act, section 2 the Secretary of State for Health is bound to:

Secure the preparation, effective carrying out and coordination of measures conducive to the health of people…including measures for the prevention and cure of diseases…the treatment of physical and mental defects, the treatment and care of the blind, the initiation and direction of research, the collection, preparation, publication and dissemination of information and statistics relating thereto, and the training of persons for health services.

The Department’s role has been defined as including:

- setting overall direction and leading transformation of the NHS and social care;
- setting national standards to improve quality of services;
- securing resources and making investment decisions to ensure that the NHS and social care are able to deliver services;
- working with key partners to ensure quality of services.

The DoH’s overall aim is to improve the overall health and well-being of the public. To carry out this role, the Department is organized into three Business Groups, who are responsible for Health and Social Care Standards and Quality; Health and Social Care Delivery; and Strategy and Business Development.

19 Eg Strategic Health Authorities, the Commission for Health Audit and Improvement, and the Commission for Social Care Inspection.
20 NHS (2005a).
In a recent review of the NHS the BMA has complained that there is too much political interference within the NHS. They call for the NHS to become free from extensive Government interference and suggest:

The Department of Health should review its changed role following the establishment of a constitution for the NHS, a board of governors, and the executive management board. Its primary role will be to provide adequate resources to deliver the constitution and to focus on public and population health and work to diminish health inequalities.21

Given the fact that the NHS remains a highly sensitive topic in political terms it is unlikely we will see the Department of Health withdrawing from management of the NHS to such an extent.

4 Quality control: regulation and inspection

There are a group of bodies whose primary responsibility is what might broadly be called ‘quality control’. They issue regulation and guidance on particular areas. These may be backed up by inspections or looser forms of enforcement. Their primary role is to ensure the provision of health services of a consistently high standard. The Health and Social Care Bill 2007 will merge the functions of the existing Healthcare Commission, the Commission for Social Care Inspection, and the Mental Health Act Commission into a new super-regulator called the Care Quality Commission. The Healthcare Commission carries out an annual ‘health check’ on NHS Trusts. It also undertakes investigations where there are particular issues of concern. In 2007 it reported that ‘On the new four-point scale, 36% were rated “good” and 4% were rated “excellent” for their quality of services. In addition, 15% of all trusts were rated “excellent” or “good” for their use of resources’.22 As these results show, the Commission does not readily hand out ‘high marks’.

5 Commissioning and planning services

5.1 Strategic Health Authorities (SHAs)

SHAs are responsible for ensuring that the health service needs of the people in their area are met. In this regard they must, as part of the NHS Plan, enter an Annual Delivery Agreement for health with the DoH for their area and seek to ensure the targets set out in that agreement are met. Their main responsibilities are:

• developing plans for improving health services in their local area;
• making sure local health services are of a high quality and are performing well;
• increasing the capacity of local health services—so they can provide more services;
• making sure national priorities—for example, programmes for improving cancer services—are integrated into local health service plans.23

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5.2 Primary Care Trusts (PCTs)

PCTs have been described as the ‘main engines of the Modern NHS’ and this is reflected in the fact that they receive 75 per cent of the NHS budget. They are responsible for finding out what the health needs of their particular area are, deciding which needs should be met and how. They will commission health care providers to meet those needs as appropriate.

5.3 Special health authorities

Special health authorities are those which provide health services to the whole of England. They are therefore to be contrasted with local health authorities who concentrate on particular areas of the country. The NHS Institute for Innovation and Improvement is one, as is the National Blood Authority.

5.4 Social services departments

The provision of social services (as opposed to health care) is the responsibility of the local authority. They can either provide the services themselves or purchase them from other providers. The distinction between social services and health care is a problematic one, as we shall see. Social services cover assistance in living independently and will cover provision of ‘meals on wheels’; assistance in washing; and sheltered accommodation, for example. These are not regarded as health care.

6 The provision of services

The providers of services are those who provide the hands-on care of patients within the NHS. ‘Primary care’ is the term used for the services provided by those people who are the normal first port of call in the case of a medical problem. They include GPs (general practitioner doctors); opticians; dentists; pharmacists; and NHS Direct (a phone service). All those offering primary care are managed by PCTs. ‘Secondary care’ is the care to which a patient may be sent by a primary carer. It involves acute and specialist services. PCTs are (confusingly!) responsible for planning secondary care. They must decide which services should be commissioned to meet people’s needs. The main bodies providing care include the following.

6.1 NHS Trusts

NHS Trusts are responsible for the provision of health services in their area. NHS Trusts were created by the NHS and Community Care Act 1990. That statute set out their responsibilities:

- their functions must be carried out ‘effectively, efficiently and economically’;
- their revenue must cover outgoings taking one financial year with another;
- they must achieve any financial objectives as may be set by the DoH.

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25 They are set up under the NHS Act 1977, s 11.
26 NHS Act 1977, Sch 2, para 6(1).
27 NHS Act 1977, s 10(1).
28 NHS Act 1977, s 10(2).
Although Trusts are accountable to the Secretary of State and must comply with directions on matters such as staffing, they are intended to have a wider degree of freedom than they did in the earlier history of the NHS. NHS Trusts are allowed to offer private health care or offer extra amenities for NHS patients for a charge. They may also borrow money within annually agreed limits. Any income generated must be spent within the Trust’s statutory powers and so the trust cannot make a profit as such.

6.2 **Foundation Trusts**

These trusts are recent creations, with the first being established in April 2004 under the Health and Social Care (Community Health and Standards) Act 2003. They are ‘independent public benefit corporations’, although they are not permitted to make a profit. They are run by a Board of Governors made up of local managers, staff, and members of the public. Foundation Trusts have far more financial and organizational freedom than other NHS Trusts. This freedom is meant to mean that they can best meet the particular needs of people in their area. Such trusts are, of course, still within the NHS and are subject to performance inspections. The intention is that by 2008 all NHS hospitals will have attained Foundation Trust status.

6.3 **Care Trusts**

As already indicated, one of the organizational problems which has bedevilled the NHS is providing a seamless service for patients between health care and social services. This becomes particularly acute where a patient no longer needs hospital care but is not able to live independently. There can then be a tension between the NHS and local authority social service departments as to who provides the care the individual may need. The Health Act 1999 created general duties of cooperation allowing local authorities and NHS bodies to pool budgets and facilitate integration. Now it is possible for local authorities and the NHS to consolidate into a single organization, known as a Care Trust. The aim of a Care Trust is to integrate the provision of social care and health care and bring to an end the ‘war’ between the NHS and social services departments over which aspect of care each organization is responsible for. There are only a small number of Care Trusts that have been created to date.

6.4 **GPs**

GPs are doctors who look after the health of those who are listed with them. As well as providing general health advice and prescribing medicines, they can also carry out simple surgical operations and give vaccinations. GPs will often work with a team of health care professionals including nurses, midwives, and physiotherapists. If the GP is not able to deal with a patient’s problem she or he will refer the patient to a hospital for tests or treatment, which may involve a meeting with a specialist consultant. Around 75 per cent of the NHS budget is allocated to Primary Care.

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32 Brazier and Cave (2007: 21).
6.5 The independent sector

Of course health and social care purchasers can contract with providers from the independent sector. All providers of independent health and social care must be licensed under the Care Standards Act 2000. All independent hospitals and care homes must register with the National Care Standards Commission. Once registered they must comply with national minimum standards and associated regulations. These are policed by regular inspections. The Commission can revoke a registration, if necessary, by application to a magistrate.

6.6 Mental Health Trusts

Basic mental health services can be provided through primary care services, such as GPs. This might include counselling and other psychological therapies. More specialist care is provided for by Mental Health Trusts or the social services department of the local authority.

6.7 NHS Direct

This is a free confidential telephone service providing medical advice.

6.8 Children’s Trusts

Following the Government’s Green Paper, Every Child Matters, the Government has announced that children’s health, education, and social services will be integrated into a single organization, to be known as a Children’s Trust. At present these trusts are being run at a pilot level.

6.9 Ambulance Trusts

These are responsible for organizing the ambulance services in their area.

7 Structural issues

We will now briefly look at some of the structural issues facing the NHS.

7.1 The provider/purchaser distinction

An important distinction is drawn between the commissioning of services and the provision of services. The concept was introduced under the Conservative Governments of the 1990s with the creation of the ‘internal market’. The idea behind it is that, by giving a PCT the power to decide from whom to purchase the health services needed, the health care providers will strive to offer an excellent service to ensure that they are selected. In short, it creates a form of competition between health care providers seeking to provide better services than each other. This, it was hoped, would drive up the

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33 Care Standards Act 2000, s 6. 34 Care Standards Act 2000, s 20.
standards within the NHS. The present Labour Government has, however, sought to distance itself from the notion of competition and instead prefers to use the concept of partnership, the idea being that health service commissioners and health service providers work together in partnership to meet the needs of the people in a particular area. Even with ‘partnership’ there is still the threat that if a health service provider is not providing services of the required standard then the health service commissioners will look elsewhere. The use of partnership rather than competition is more about changing the atmosphere of relationships between providers and commissioners than changing the central idea that providers should keep striving to offer a high level of service. Under the NHS reforms currently under consideration patients will start to play some role as commissioners. In the past patients would have had no choice within the NHS other than to accept the services offered by their GP. The proposal is that if local services cannot offer treatment within six months patients can choose alternative providers, including the private sector.

7.2 The use of Arm’s Length Bodies (ALBs)

As can be seen from the list of bodies involved in the structure of the NHS Arm’s Length Bodies (ALBs) play a significant role. These are commissions, institutes, and authorities who are separate from Government but are answerable to it, and are in charge of regulating particular areas. Although the list is long it is shorter than it would have been but for a recent review of ALBs, which reduced their number in a bid to save some half a billion pounds in the time period 2003–2008. In 2003/04 there were 38 ALBs, who spent a total of £4.8 billion, including operating costs of £1.8 billion. The review found a widespread perception in the NHS that the ALBs were associated with a considerable level of bureaucracy. The review has therefore proposed a reduction in the number of ALBs to 20, as well as cuts in their budget.

Supporters of ALBs emphasize that they enable the regulation of sensitive areas of health care to be provided free from political interference. Take, for example, the Human Fertilisation and Embryology Authority which must issue guidance on sensitive issues relating to embryo research and advances in reproductive technology. If the issue were to be decided by the Government this would create concerns that the regulation would reflect what the Government would think was acceptable to the general public, rather than what was scientifically and ethically appropriate. But opponents of ALBs may claim that this is precisely the problem with them. It is claimed that these bodies are not accountable and are made up of professionals working in the area who are out of touch with the feeling and thoughts of ordinary people.

7.3 Decentralization

One of the key themes in the current NHS is to devolve power to local PCTs and front line staff. The argument is that front line staff are in the best position to know what patients in their area of the country need and how best to meet those needs. The independence given to PCTs is seen as key to enabling local NHS bodies to meet needs in their area. The DoH has said it will provide resources and ‘lead the transformation’, but
that it will not seek to manage at a hands-on level.39 As one document put it, ‘it will steer more and row less’.40

An important part of the move to decentralization is the use of Foundation Trust hospitals, which have significantly greater freedom over their budgets than the NHS Trust hospitals. The aim is that by 2008 all NHS hospitals will have reached Foundation Trust status. The claimed benefit of the status is that NHS Foundation Trusts will be able to provide relevant care for their patients because they have been set free from government control.41 But, there are some concerns about Foundation status. Some of those awarded the status have failed subsequently to achieve the required ‘star status’ and the restrictions on not making profits have been criticized by some. The strength of these concerns is reflected by the fact that the Healthcare Commission has been asked to examine the experiences of the first 20 Foundation Trust hospitals.

One of the consequences of decentralization is a difference in practice between different PCTs. A 2006 King’s Fund Report found that, for example, while Islington PCT spent £406 per head on mental health services, Bracknell Forest PCT spent only £56.42 This is a huge difference and presumably there were other services that Bracknell were paying for instead that Islington were not.

7.4 ‘Democratic accountability’

Another theme in the structure of the NHS is democratic accountability. This is the notion that the public itself should have the opportunity to direct the future of the NHS and call it to account in areas where it is failing. The Health and Social Care Act 2000, section 11 therefore places a duty on NHS Trusts, PCTs, and Strategic Health Authorities to make arrangements to involve, and consult, patients and the public in service planning and operation, and in the development of proposals for changes.

One of the major ways this is done is through the Patient and Public Interest Forums, but evidence from these indicates the difficulties in the notion of democratic accountability. Claims have been made that it has been very difficult to find members of the public who are willing to be involved in forums, and one commentator has suggested that ‘many of the forums are virtually inactive’.43

7.5 Change

The pace of change in the structures and workings of the NHS is remarkable. Bodies are created and removed with remarkable speed. One leading commentator has stated that since 1982 there has been some kind of ‘organisational upheaval’ almost every year.44 To some this may indicate how seriously governments have been taking the need to improve the quality of service offered by the NHS. Others have claimed that institutional reform has been a smokescreen for hiding really important issues,45 in particular that the supply of NHS services depends increasingly on private providers, rather than public bodies. One important consequence of this is that the Human Rights Act only applies to a public authority and it has been held that a private care home is not a public authority for these purposes.46 This means that a patient in an NHS care home can rely

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39 DoH (2001c).
40 DoH (2001c: 9).
41 Monitor (2005).
42 King’s Fund (2006).
43 Lewis (2005: 1).
45 Klein and Williams (2000).
46 *YL v Birmingham CC*[2007] UKHL 27.
on the Human Rights Act 1998 if their rights have been interfered with; but a patient in a private care home may not be able to.

7.6 Money

Like it or not, money is central to the way the NHS operates. Despite increased funding of the NHS in recent years there still appear to be serious financial difficulties facing many parts of the NHS. A report by the think-tank the King’s Fund noted:

By 2007/8, annual spend will be 40 per cent higher in real terms than it was five years earlier. But despite the increased funding, the NHS is in deficit. In 2005/6 NHS trusts in aggregate overspent by more than £1.2 billion, and the NHS as a whole overspent by more than £500 million. More than 60 trusts incurred significant deficits, and stories of staff reductions, service cutbacks and ward closures are widespread.47

It is not possible here to discuss all of the issues facing the NHS. What follows are, however, some selected topics that are of particular interest and controversy.

8 Public health: infectious diseases

The main legislation controlling the behaviour of infectious diseases is surprisingly old, being the National Assistance Acts of 1948 and 1951 and the Public Health (Control of Diseases) Act 1984.48 It is notable how much of the responsibility for control of infectious diseases rests with local authorities, rather than central government, and that the emphasis is on protection of the public rather than upon individual human rights. The legislation must be construed with the Human Rights Act very much in mind and so any public authority exercising the powers must act in a way which is compatible with an individual’s human rights if possible.

The Public Health Act 1984 gives local authorities powers to control the spread of diseases. The list of diseases covered in the Act is: cholera, plague, relapsing fever, smallpox, and typhus. These are known as ‘notifiable diseases’. The list has been added to by the Secretary of State49 and now includes over 20 diseases including AIDS, leprosy, malaria, and rabies. The powers to control diseases include the following.

8.1 Notification

Under the 1984 Public Health Act a doctor must notify the local authority of anyone whom she or he suspects of having a notifiable disease. If the doctor does not notify ‘forthwith’ then in theory a criminal prosecution could follow. The local authority is required to notify the Health Authority within 48 hours. For some diseases (eg rabies) the Government’s Chief Medical Officer must be notified immediately.

8.2 Investigative powers

In order to acquire information needed to tackle notifiable diseases there are obligations on occupiers of premises, employers, and head teachers to provide information that is

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reasonably required of them by a local authority’s medical officer. Most dramatically there is power to compel someone to undergo compulsory medical examination under order from a Justice of the Peace under the Public Health Act 1984, section 35. The order can only be made if:

(a) there is reason to believe that the person is or has been suffering from a ‘notifiable disease’ or carries an organism capable of causing a disease;

(b) it is in the interests of the person, her or his family, or the public that the person be examined; and

(c) the doctor treating the person (if there is one) consents to the making of the order.

If this seems draconian, worse follows. The order can be made ex parte50 (ie at a hearing of which the individual has no notice) and can be made in relation to a group of people if it is thought one of them has the disease.51 If an order is made then there is a power to enter private premises to carry out the examination.52

8.3 Powers to remove, isolate, and detain

In an extreme case there are powers to detain an individual in hospital in the name of public health, even without that person’s consent. These powers are found in the Public Health (Control of Disease) Act 1984. The National Assistance Act 1948, National Assistance (Amendment) Act 1951, and Mental Health Act 1983 provide powers where the primary concern is for the care of the individual, rather than the prevention of the spread of disease. For example, section 37 of the 1984 Act authorizes a magistrate to order that a person with a notifiable disease to be removed to hospital. There are three requirements that must be satisfied before such an order can be made:

(a) proper precautions to prevent the spread of diseases cannot be (or are not being) taken;

(b) the absence of precautions means that there is a serious risk of infection to others,53 and

(c) suitable hospital accommodation is available.

The order can be made ex parte (ie without the person having an opportunity to put their side of the case). There are also provisions which can prevent a person suffering from a notifiable disease from using public transport, public libraries, or schools.54 It may be that some of these provisions fail to adequately protect the rights under article 5 of the European Convention on Human Rights (ECHR).55

50 Once the order has been made an appeal can be made to the Crown Court against it: Public Health (Control of Disease) Act 1984, s 67.
51 Public Health (Infectious Diseases) Act 1984, s 36.
52 Ss 35(2) and 36(2). There are further powers to order examinations of those in specific jobs such as midwives or dairy workers.
53 Montgomery (2003: 31) notes that there is an ambiguity here over whether it is the risk or the severity of harm that is taken into account in assessing the risk as dangerous.
54 Public Health (Control of Diseases) Act 1984, ss 20–25.
8.4 Vaccination

Immunization programmes are now a widely accepted part of the medical treatment of children. Such programmes have been a highly effective response to smallpox and other illnesses. However, in the UK, concerns over the MMR vaccine in particular have seen a drop in the number of children being vaccinated. As that controversy has highlighted, vaccinations are not compulsory and parents are free to decide not to have their children vaccinated. In Re B (A Child) (Immunisation) the children’s parents (who had separated) could not decide whether or not have their children vaccinated and the issue was brought to court. The Court of Appeal decided that the question was simply one of what was in the child’s welfare. Having heard expert evidence they concluded that it would be in the child’s interests to be vaccinated.

8.5 Compulsory care

There are very few circumstances in which people are forced to receive treatment against their wishes. There is a special regime for those with mental health problems which will be discussed in Chapter 10. Here we will focus on the compulsory treatment of people for public health concerns. The following appear to be the only circumstances in which a person can be forced to receive treatment in order to protect the public health:

(i) Infectious diseases. The Public Health (Control of Disease) Act 1984, section 13 permits the Secretary of State to make regulations ‘with a view to the treatment of persons affected with an epidemic, endemic or infectious disease’. There is some debate whether this enables the Secretary of State to issue regulations permitting compulsory treatment. Kennedy and Grubb argue not, on the basis that the wording is ambiguous, and given the well established common law right to refuse treatment (now reinforced by the Human Rights Act 1998) such rights could not be overridden without the most explicit statutory provision.

(ii) Cleansing of vermin. Under the Public Health Act 1936, section 85 a person may be cleansed of vermin under a court order, compulsorily, as long as the court is satisfied that it is necessary to cleanse the person.

(iii) National Assistance Act 1948. Section 47 allows people who are suffering from ‘grave chronic disease’, or are ‘aged, infirm or physically incapacitated’, and are living in ‘insanitary conditions’ to be removed if they are not able to provide proper care and attention for themselves and are not receiving that from others. However the section only authorizes the person to be removed to a hospital. There is no explicit power to permit compulsory treatment.

(iv) Fluoridation. Fluoride can be added to water, especially to assist in the dental health of children. This is widely seen as the most effective way of promoting children’s dental health. However, this is controversial as it means fluoride is added to the water supply for the whole community. The complaint is that fluoridation makes it very difficult for someone who did not want to drink fluoride to avoid it. The Water Industry Act 1991, sections 87–91 permit water suppliers to add fluoride when asked to do so by a health authority. However, water suppliers are not required to do so. Since 1985 there have been no new fluoridation schemes. This is in part due to privatization. Private

companies do not want the ‘hassle’ of fluoridation and the aggravation they may receive from customers who object.\(^59\) Further, any proposal to fluoridate must go through a public consultation process. Those groups opposed to fluoridation can dominate any consultation process.

The issue of the non-consensual treatment and detention of patients raises important human rights issues. The ECHR, article 5(1)(c) specifically permits the lawful detention of a person to prevent the spread of infectious diseases. However, the infringement of human rights must be justified in the name of public health, necessary in a democratic society, and be proportionate.\(^60\) If any of the powers mentioned above are to be used it will need to be shown, therefore, that there are no less coercive means of preserving the public health, and that the danger to the public is sufficiently serious as to justify the interference with human rights.

The spread of HIV has given the issue of controlling infectious diseases a particular contemporary resonance. In the debate a number of issues have been raised. It is not possible here to canvass all of the issues this important debate raises. The further reading will direct you to where to look for an in-depth discussion. One issue is whether or not there should be compulsory testing among everyone or certain groups of people. To test someone against their wishes appears to be contrary to fundamental principles of medical law and ethics. However, compulsory testing may be seen by some as essential if the Government is to have clear picture of the extent of HIV infection and even to ensure the safe treatment of a patient. So far the Government had not permitted widespread non-consensual testing for HIV, although it has authorized the anonymized non-consensual testing of blood of those attending antenatal and STD clinics. Further, some of the powers under the Public Health Act 1984 now apply to AIDS, and compulsory examination and removal to hospital are theoretically possible. Given that with responsible behaviour it is possible for an HIV positive person to be non-contagious these are controversial provisions, which have been described as permitting ‘drastic interventions into the liberty of those who have or are suspected to have HIV’.\(^61\) There is no reported case in which these powers have been used.

Another issue is that recent developments in criminal law mean that if X, knowing that he is HIV positive, has sexual relations with Y, without Y consenting to sexual relations aware of X’s condition, then X can be guilty of inflicting grievous bodily harm if Y becomes infected as a result.\(^62\) In effect this requires a person who is aware that she or he is infectious to inform her or his sexual partners of their condition before sexual activity. To some this is an effective means of promoting public health and protects the sexual and bodily autonomy rights of individuals.\(^63\) To others this is an improper interference with the sexual freedom of those who are HIV positive and may discourage people from taking tests to discover whether they are positive.\(^64\)

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\(^{59}\) See *R v Northumbrian Water Ltd ex p Newcastle and North Tyneside HA* [1999] Env LR 715 for an example of a legal challenge to proposed fluoridation.

\(^{60}\) *Acmanne v Belgium* (1984) 40 D&R 251.


\(^{62}\) The offence is under the Offences Against the Person Act 1861, s 20: *R v Dica* [2004] 3 All ER 593.

\(^{63}\) *Herring* (2005).

\(^{64}\) *Wacht* (2005).
9 Public health: prevention

The traditional approach to medicine has been reactive: to diagnose the sick and offer them treatment. Increasingly the importance of preventative measures has been emphasized. Hence the NHS sees itself not only as offering treatment to the ill, but seeking to promote good health for the general public.65 In economic terms this makes sense. If the Government can reduce the incidence of illness or accident there will be less call on the NHS’s resources. Obesity, smoking, increasing drug and alcohol misuse, and sexually transmitted diseases all add to the pressure on the NHS.66 Without preventative health the NHS would simply be overwhelmed by the needs of those suffering ‘preventable illnesses’.67 Indeed under article 11 of the European Social Charter the Government is required to remove the causes of ill-health, prevent disease, and advise individuals on how to look after their own health.

It is also interesting that the notion of public health has been developing. In the past its goal was simply trying to reduce the death rates among the general population. However, consider the World Health Organization’s definition of health:

a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.68

With this in mind actions which can be said to be public health issues could include things like the provision of recreation and park facilities which might never have been included in earlier understandings of the term.

But the key issue in public health is the role the Government should play in some of the major public health issues: smoking, obesity, and alcohol misuse, for example. Should the Government be actively seeking to prevent unhealthy lifestyle choices or is that too interventionist and rather should the Government’s role be to encourage and enable people to live more healthily? There are some areas where it appears less controversial for the Government to intervene in the name of public health. Environmental issues are one. Clean air69 and water70 are, of course, essential to the nation’s good health. But in areas such as diet, where the Government is seen as too interventionist, it is said by some that we are suffering under a ‘nanny state’.

There are two issues here. The first is practical. There is a limit to what the Government can do in some areas. Programmes of vaccination and sanitation can be relatively easy to implement. But even if the Government wanted to force everyone to eat five portions of fresh fruit and vegetables a day, that would be almost impossible to implement. Second, is the theoretical issue, which concerns the extent to which it is the role of the Government to influence people’s lifestyle choices. It has been said we have a ‘new public health’.71 Rather than the Government seeking to force people to adopt healthier lifestyles, much more effort is put into persuading individuals to take responsibility for their own health and make ‘healthy choices’.72 A recent Government Paper, Saving Lives: Our Healthier Nation, suggests that there needs to be a ‘national contract’ between individuals, communities, and Government to reduce death rates and improve health. The Government
is seeking to avoid claims that it is encouraging a ‘nanny state’, while not standing by as the health of the nation deteriorates and the burden on the NHS increases. The NHS Modernisation Board in 2005 stated:

The prime responsibility for improving the health of the public does not rest with the NHS, nor with the Government, but with the public themselves. However, it is wrong to say that Government has no role; it must provide clear information, helping more people to make healthy choices, by creating a supportive environment in which they can be helped to stop smoking, improve their diets and take more exercise.

To some critics, however, these ways of presenting public health issues, focussing on individual responsibility, hide an important point and that is that political and social factors play a crucial role in people’s health. Poverty levels and socio-economic groupings can have a huge impact on an individual’s health. The emphasis on helping people to be healthy ignores these and can be said to be an attempt to shift responsibility for health away from Government and towards individuals.

It should also be remembered that although health is an important value for other people there are other things in our lives that we care about: liberty, autonomy, happiness etc. So health should never be regarded as a value worth pursuing at all costs.

Obesity

There is widespread acceptance that obesity is a problem. Most adults in England are overweight and one in five (around 8 million individuals) are obese. It has been estimated that by 2050 60 per cent of men and 50 per cent of women will be obese (Foresight (2007)). At a simple level the cause is seen as an increasingly sedentary lifestyle, and poor eating patterns. However, in fact a host of more complex factors are behind these statistics. Obesity, it has been said, causes 30,000 deaths a year and shortens life expectancy by nine years. It has been estimated that the annual cost to the NHS of obesity is half a billion pounds (Committee of Public Accounts (2005)). Of course not everyone accepts that there is an ‘epidemic’ of obesity (Social Issues Research Centre (2005)). What is the Government to do?

In the Government’s White Paper on Public Health (Making Healthy Choices Easier) three core principles were identified (para 5.101):

- **informed choice**: Government providing support through credible information to allow people to make their own decisions about choices that impact on their health;
- **personalization**: supporting people to make healthy choices, especially for deprived groups and communities; and
- **working together**: through effective partnerships across communities.

This is a delicate balance between encouraging people to adopt healthier lifestyles without being seen to be bossy. Consider the following statement by Tessa Jowell, a health minister (2004):

We do however live in a time where there is an almost allergic reaction to any suggestion that Government can or should influence private behaviour (and obesity is a function of

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73 King’s Fund (2004).
74 Modernisation Board (2005).
75 Rees Jones (2003).
76 Häyry (2006).
2 THE STRUCTURE OF THE NHS

private behaviour)… Providing people with the means to understand and take informed decisions; removing some of the obstacles to changing behaviour that may be beyond the means of individuals; getting out the wider considerations and context—that is not being a nanny state, but the enabling role of good Government.

Some of the tensions between these aims can be seen in the proposals in the Government’s White Paper on Public Health designed to combat obesity:

- a new health advice service called Health Direct to be available over the phone, internet and digital TV;
- a personal health guide and NHS health trainer for everybody;
- working with the food and drink industry to develop voluntary codes on food and drink promotion to children. If these are not satisfactory the Government will introduce legislation;
- traffic light labelling for supermarket foods indicating how healthy they are;
- giving pregnant women vouchers enabling them to buy fresh fruit and vegetables, milk, and infant formula;
- encouraging children to cycle to school;
- monitoring the nutritional value of school meals through the school inspection regime.

Note how it seems more acceptable to be ‘nannying’ to children than adults.

10 Rationing

It would be wonderful if everyone who needed medical treatment could receive it. However, there appears to be a widespread consensus that to do so is simply not feasible. There are not enough medical professionals and not enough money to provide a comprehensive service. It would simply bankrupt the NHS to give every person the treatment they wanted. One survey of a PCT in the NHS found that the panel which made decisions about funding new treatments was faced with applications that would have cost £44 million, but had only £5 million available. As a result some means must be found to restrict access and decide, given the limited funds available, who should receive which treatment. This is generally known as rationing.

The question, from a legal perspective, can be looked at in two ways. One is to focus on health care authorities and ask in what ways is it lawful for them to restrict access to health care and how they should make rationing decisions. The other is to focus on patients and to ask whether we have a right to health care treatment and if so of what kind. This is not to ask the same question in a different way. Consider a case where a cash-strapped health authority fails to provide urgent health care treatment to a patient on economic grounds. It may be found that the individual’s right to health care was infringed, but that the health authority acted reasonably in allocating its resources in the way it did. In such a case the claim may be better made against the Government in failing to provide sufficient funding for Trusts to be able to provide the care required. There could also be a case where a patient was denied health care and, although the court did

77 See Light (1997) for an argument that this assumption should be challenged.
78 Iqbal, Pryce, and Afza (2006). They also discuss how in practice PCTs make rationing decisions.
not think that there was a right to the kind of care in question, that the health authority had acted improperly in allocating resources in such a way.

10.1 What does rationing mean?

Rationing is said to occur where there is only a limited resource of health care and the decision is made to offer it to some people, but not others. Rationing does not therefore arise where a patient is not offered treatment because it is not clinically effective.

A central issue in rationing is the definition of a health care need. If a person who has no health care need, then denying them ‘treatment’ does not really involve rationing. However, the notion of ‘need’ is unclear. Andreas Hasman, Tony Hope, and Lars Østerdal\(^79\) have suggested three possible meanings of need in this context. One definition of need is that the patient is below an accepted state of well-being and there is a treatment which can improve their condition. A second is that there is a need if a treatment will raise the patient’s well-being from below a certain threshold to above it. A third is that a treatment will offer a patient a significant increase in well-being. It is rarely articulated which of these three is taken to be a need.

Rationing within the NHS can happen at three levels. First, there is the decision as to how much money the Government allocates to health, as opposed to other calls on public expenditure. Second, there is the decision as to how money will be allocated to different bodies within the NHS. Third, there is the decision by the bodies as to how the money will be spent to meet the needs of different people in their area.

10.2 The law on rationing

10.2.1 Statute

The National Health Services Act 1977 obliges the Secretary of State in section 3 to promote:

- a comprehensive health service designed to secure improvements in (a) in the physical and mental health of the people of [England and Wales], and (b) in the prevention, diagnosis and treatment of illness.

In \(R v\) Secretary of State for Social Services \(ex p\) Hinks\(^80\) the Court of Appeal emphasized that even where the Secretary of State for Health had a duty under the NHS Act 1977, section 3 to provide services (in that case orthopaedic surgery), the duty was to provide the services ‘to such an extent as he considers necessary to meet all reasonable requirements such as can be provided within the resources available’.\(^81\) It is therefore clear that it is permissible to take into account financial considerations when deciding whether to offer treatment to a particular patient or group of patients.\(^82\)

Throughout the 1977 Act the following phrase appears: ‘to such extent as he [the Secretary of State] considers necessary to meet all reasonable requirements’. This applies to, \textit{inter alia}, duties to provide hospital accommodation and medical, dental nursing, and ambulance services. This makes the enforcement of the Secretary of State’s obligations difficult. It would be very difficult to show that the Secretary of State had breached

\(^79\) Hasman, Hope, and Østerdal (2006).
\(^80\) (1980) 1 BMLR 93.
\(^81\) Ibid, at 95.
\(^82\) \(R v\) Sheffield HA \(ex p\) Scale [1995] 25 BMLR 1.
her or his statutory duty by failing to provide a service which she or he thought reasonable. One of the few duties not so limited is the requirement to provide for the medical examination and care of state school pupils at appropriate intervals (section 3(1)).

So it is very unlikely that the Secretary of State would be found to be in breach of a statutory duty. Even if she or he was, the mode of enforcement would be by a claim for breach of statutory duty. However, in *Re HIV Haemophiliac Litigation*83 the Court of Appeal accepted that the 1977 NHS Act did not provide the basis of an action for breach of statutory duty.84 All of this indicates that a claimant seeking to challenge a rationing decision is unlikely to have much joy basing her or his claim on breach of statutory duty under the 1977 NHS Act.

There is a duty on PCTs to arrange GP, dental ophthalmic, and pharmaceutical services.85 They must ensure that everyone can find a GP and deal with complaints about their GP that cannot be resolved within practices. Under regulations, the role of a GP is to give patients on their lists ‘all necessary and appropriate personal medical services of the type usually provided by a general medical practitioner’.86 This is not a very precise duty and again it would only be in cases involving the most blatant of failures that the duty could be enforced.

10.2.2 European law

**European Angles**

Claims under European law have been considered in the following case which discusses whether a patient who is refused treatment, or who faces a lengthy delay in obtaining treatment, can seek to have the operation conducted in another European Country and require payment for it from the NHS.

**KEY CASE** *R (on the application of Watts v Bedford Primary Care Trust and Secretary of State for Health 2003 EWHC 2228 and [2004] EWCA 166 and Case C-372/04)*

Ms Watts suffered constant hip pain and had limited mobility, caused by osteoarthritis. She was on an NHS waiting list for a hip replacement and given a waiting time of approximately one year. She applied to have the operation performed in France using the form E112 procedure under article 22 of Regulation 1408/71, which conferred a right to be treated in another Member State at public expense where such treatment was not available within the time normally necessary for obtaining the treatment in the Member State of residence. The PCT refused. One of the reasons given was that because she would receive the operation within the normal waiting time she would not suffer undue delay.

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83 (1990) 41 BMLR 171. See also the House of Lords decision in *X v Bedfordshire* [1995] 3 All ER 353 where it was noted that there has never been a case of a successful claim for breach of statutory duty in legislation dealing with social welfare issues.

84 Although see *R v Ealing DHA ex p Fox* [1993] 3 All ER 170 in which, *obiter*, it was suggested that mental patients could rely on the NHS Act 1977, s 3(1) for an action in breach of statutory duty.

85 NHS Act 1977, ss 29, 35, 38, and 41.

86 NHS (General Medical Services) Regulations 1992, Sch 2, para 12(1).
In her application to the High Court she sought to rely, *inter alia*, on article 49 EC and article 22 of Regulation 1408/71. It is useful to look at both the first instance and the Court of Appeal decision.

**Mumby J:** In relation to the article 49 (providing a freedom to obtain services) claim Mumby J held that the article did apply to medical and hospital services, although following the decision of the ECJ in *Geraets-Smits v Peerbooms* [2001] ECR I–5363, such a claim could only succeed if there was prior authorization for the treatment from the UK. But the payments only had to be made if there was not effective treatment available in her home country without ‘undue delay’. In so holding he rejected an argument that *Geraets-Smits* did not apply in countries where health care was funded through general taxation. Justice Mumby rejected the PCT’s interpretation of undue delay being ‘a normal waiting time’ for the country in question, but held that the concept required a consideration of what was reasonable bearing in mind whether the patient was in pain, whether there had been repeated delays in treatment, and whether the patient would suffer deterioration if the treatment was delayed. Taking these factors into account a delay of three to fourth months was not undue. He did suggest (at para 158) that a delay of a year leaving a patient in considerable pain and with mobility difficulties could be regarded as undue.

In relation to article 22 of Regulation 1408/71 the availability of treatment ‘within the time normally necessary for obtaining the treatment in the Member State of residence’ referred to normal within the NHS. Her delay was not abnormal by the standards of the NHS. So that claim failed too.

**Court of Appeal:** The Secretary of State appealed against Mumby J’s decision, arguing that rulings of the European Court of Justice which had held that institutions providing medical services in one Member State might be obliged to reimburse the cost of a patient’s treatment in another Member State did not apply to the NHS. Alternatively, if that case law was applicable to the NHS, he argued that the concept of ‘undue delay’ should be interpreted by reference to a properly operated NHS.

The Court of Appeal confirmed Mumby J’s ruling that article 49 EC did apply to NHS Treatment. The decision in *Muller-Faure* [2004] 2 CMLR 33 applied to a State-funded NHS as to other forms of health systems in Europe.

The proviso in article 22 of Regulation 1408/71 that a person should be authorized to go to another Member State for treatment applied where she or he could not be given such treatment ‘within the time normally necessary for obtaining the treatment in question in the Member State of residence, taking account of his current state of health and the probable course of the disease’ this did not require a consideration of ‘normal waiting times’. Rather it focused on clinical judgment and the impact of the delay on the particular individual concerned.

The Court of Appeal went on to explain that although these findings represented the current law they created considerable problems for the UK, with its NHS system. It sought a preliminary ruling from the European Court clarifying the application of article 49 EC and article 22 of Regulation 1408/71 in the light of the specific features of the NHS. A ruling would also be sought as to the basis on which the NHS was obliged to pay or reimburse costs if it authorized medical treatment for a patient in another Member State.

**ECJ:** The ECJ started their analysis by emphasizing that a UK citizen could only require the NHS to fund overseas treatment if the NHS had given its authorization to the treatment. In deciding whether to give authorization the NHS had to take into account the clinical needs of the patient. In particular an objective assessment had to be made of the patient’s medical condition, the history and probable course of their illness, the degree of pain they were in, and/or the nature of their disability. If the treatment could only be offered within the NHS after an unacceptable delay then the NHS had to authorize treatment overseas. Whether the delay was unacceptable or not depended on the clinical factors just listed. Economic factors and budgetary constraints were not relevant considerations.
The impact of this decision is, therefore, that a patient can require the NHS to fund treatment overseas if treatment on the NHS will only become available after an unacceptable delay. It is not open to the NHS to claim that the delay is acceptable given the monetary difficulties facing an NHS Trust. Trusts will now need to set up schemes to deal with applications for those seeking authorization for funding for treatment in other European Countries. Such a scheme will have to be non-discriminatory and readily accessible. It is likely that this decision will assist those patients with sufficient education and articulacy to make the relevant claim. Cynics might see it as providing an effective way of jumping the queue to treatment for the middle classes. Christopher Newdick complains that ‘then those willing and able to travel abroad will have greater access to expensive treatments than those who are too ill, old or disabled to travel’.

10.2.3 Judicial review

The most common way of using the courts to challenge a rationing decision is judicial review. Such attempts have rarely succeeded. There are three main bases on which judicial review can be sought:

(i) The decision was illegal. For example, that it was a decision the PCT had no power to make.

(ii) The decision was irrational or unreasonable. Unreasonable in the context of judicial review has a special meaning: it must be shown that the decision was so unreasonable that no reasonable decision maker would have made it.

(iii) There was procedural impropriety in the making of the decision.

Most applications in this context will involve the unreasonableness ground. As already indicated this is difficult to prove because it is not enough to show the decision was not the best one that could be made, but rather one that no reasonable decision maker could have made. The following are some of the key points that emerge from the case law:

(i) Although there is a statutory duty to provide medical treatment, that is not an absolute duty, because resources are finite. In *R v North and East Devon Health Authority ex p Coughlan* the Court of Appeal said that, in exercising judgments about resource allocation, the Secretary of State for Health (and therefore all bodies which took their powers from him) had to bear in mind the comprehensive service which he is under a duty to promote. However, as long as he pays due regard to that duty, the fact that the service will not be comprehensive does not mean that he is necessarily contravening [his statutory duty]. The truth is that, while he has the duty to continue to provide a comprehensive free health service and he must never disregard that duty, a comprehensive health service may never, for human, financial and other resource reasons, be achievable. In exercising his judgment

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87 See McHale (2007) for a useful analysis of the decision.
88 McHale (2007).
89 Newdick (2007: 244).
90 In *R (on the application of Cavanagh) v Health Service Commissioner* (2005) 91 BMLR 40 it was held that the Health Service Commissioner could not hear a complaint about a rationing decision.
91 The detail of the law generally on judicial review can be found in textbooks on administrative law.
92 In *R v Secretary of State for Social Services and others ex p Hincks* (1980) 1 BMLR 93.
93 [2000] 3 All ER 850.
the Secretary of State is entitled to take into account the resources available to him and the demands on those services.

(ii) A fixed policy that is not responsive to the needs of individuals may be unlawful. In *R v NW Lancashire HA ex p A*[^94] a rigid policy against funding gender reassignment surgery was found to be unlawful, as it fettered the discretion of the authority and failed to enable it to consider the individual facts of each case. Of course a policy which stated that generally a certain kind of treatment would not be available would be permissible, as long as each case was considered individually.

(iii) Patients should have a chance to explain why they should be given treatment and to hear why they are being denied it.[^95] This does not mean that the patient should be able to directly address the decision maker, but that the patient’s views must be properly considered.[^96]

(iv) A successful judicial review challenge could be brought if, in reaching its decision, the NHS body had taken into account irrelevant considerations or failed to take into account relevant considerations. It is clear that the likelihood of success of the treatment[^97] and NICE guidelines would be relevant factors. So in *R v Derbyshire HA ex p Fisher*[^98] it was found to be improper to fail to follow an NHS circular without explanation. Obviously a decision which was based on sex or race would also be unlawful. It is less clear whether age would be an impermissible factor. It certainly could be taken into account if a patient’s age meant that the treatment was less likely to be effective. We shall consider this issue in more detail later in this chapter.

(v) If a public body has created a legitimate expectation that a certain form of treatment will be provided, and unfairly alters its policies to the disadvantage of those who have relied on the expectation, then a successful claim could be sought. In *R v North and East Devon HA ex p Coughlan*[^99] it was found that the applicant had been assured by the Health Authority that she would have a home for life in a residential facility managed by the Health Authority. Her legitimate expectation rendered the later decision to close the facility unlawful.

(vi) It is unlikely that a clinical assessment concerning treatment will be found unreasonable. In *R v Secretary of State for Social Services ex p Walker*[^100] the applicant was the mother of a child who needed an operation to rectify a congenital heart defect. The difficulty was that there was a shortage of beds on a neonatal unit. Other children kept being assessed to be in greater need than the applicant’s child and she sought to challenge the health authority’s decisions. The Court of Appeal accepted that the local authority had acted properly in preferring to give cots to the most urgent cases. This was, in effect, a clinical decision and not open to challenge in the courts. Similarly courts will not force doctors to provide care that in their clinical judgement they think inappropriate.[^101]

(vii) It is not yet clear how the Disability Discrimination Act 1995 will impact on rationing decisions. The Act makes it illegal for service providers to discriminate on the basis of a disability. That is a ‘physical or mental impairment which has a substantial and long-term adverse effect on [a person’s] ability to carry out normal day-to-day activities’.[^102]

[^94]: [2000] 2 FCR 525.
[^95]: *R v Ethical Committee of St Mary’s Hospital ex p Harriott* [1988] 1 FLR 512.
[^99]: [2000] 3 All ER 850.
[^100]: (1987) 3 B MLR 32.
[^101]: Disability Discrimination Act 1995, s 1(1).
[^102]:
This would mean, for example, that it would be unlawful for a health authority not to allocate resources to someone to deal with a physical problem simply on the grounds that they suffered from a mental illness.

(viii) Financial considerations can be taken into account in deciding whether to offer treatment. The courts have tended to take the view that it is appropriate for health authorities in deciding whether to offer treatments to take into account their limited resources. When doing that it is for the health authorities and not the courts to make the assessment. The question of the relevance of financial considerations came dramatically to a head in the following case:

**KEY CASE**  
**R v Cambridge HA ex p B [1995] 2 All ER 129**

B was a ten year old girl with leukaemia. A bone-marrow transplant had been attempted but it was unsuccessful. Doctors in London and Cambridge believed she had only six to eight weeks to live and that any further treatment would be inappropriate. However, B’s father did not accept this assessment and found a professor in London and doctors in the United States who would have offered the girl further treatment. The professor admitted that his proposal of chemotherapy and a possible second transplant was experimental and not standard. The Health Authority supported the decision not to offer further treatment. They explained: ‘the substantial expenditure on treatment with such a small prospect of success would not be an effective use of resources’. The father sought judicial review of the decision. At first instance before Laws J he succeeded. Justice Laws emphasized the girl’s right to life under article 2 of the European Convention on Human Rights. This meant that compelling reasons had to be provided to justify preferring the needs of other patients over her. Simply stating that resources were limited was not sufficient, the health authority had to state explicitly which other calls on its funds meant that it was not able to offer her treatment.

The Health Authority was, however, successful in its appeal to the Court of Appeal. The Court emphasized it was not for the courts to look at the merits of the local authority’s decision. It was not the courts’ job to assess whether the local authority’s distribution of resources was appropriate. Sir Thomas Bingham held:

Difficult and agonizing judgements have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum of patients. That is not a judgement which the court can make.

The case is fascinating for its contrast between the approaches of Laws J at first instance and the Court of Appeal. The Court of Appeal used the standard unreasonableness test. They found that sensitive decisions on resource allocations can only in exceptional cases be said to be unreasonable. This was not such an exceptional case. The main point for the Court of Appeal was that the court should in cases of judicial review not be considering the merits of the decision, but rather the process by which it was reached. Justice

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Laws by contrast regarded the unreasonableness test as inappropriate in cases like this where there are fundamental human rights at stake; here the right to life. The progress of the case following the Court of Appeal’s judgment is revealing. B’s father took her to the United States and she received treatment which was paid for by an anonymous donor. The early signs were promising: B’s leukaemia went into remission, but several months later she fell ill again and died in May 1996. Whether this vindicated the health authority’s view that the treatment was not clinically appropriate, or B’s father’s views that the treatment enabled her to have several more happy months of life, something on which no value can be placed, is a matter of debate.

However, the decision in B may suggest that it is very unlikely that a rationing decision will successfully be challenged before the courts. It is worth remembering the decision in *R v NW Lancashire HA ex p A and G*\(^\text{107}\) where the Court of Appeal held the decision to bar funding of gender reassignment surgery to be unlawful. There Auld LJ stated:\(^\text{108}\)

\[...\] in establishing priorities—comparing the respective needs of patients suffering from different illnesses and determining the respective strengths of their claims to treatment—it is vital: for (1) an authority accurately to assess the nature and seriousness of each type of illness, (2) to determine the effectiveness of various forms of treatment for it and (3) to give proper effect to that assessment and that determination in the application of its policy.

It is not quite clear whether Auld LJ was intending to suggest that a health authority which failed to consider these factors would be acting lawfully and could be subject to judicial review; or whether he was merely indicating good practice. If he was suggesting that a failure to follow this advice could lead to a successful legal challenge then this suggests a far greater willingness by the Court of Appeal to examine the reasoning process by which a rationing decision was made than appeared in B.

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**KEY CASE**  
**R (Rogers) v Swindon NHS Primary Care Trust [2006] EWCA Civ 392**

Anne-Marie Rogers sought a judicial review of the decision of her PCT to refuse to fund her treatment with Herceptin (an unlicensed drug). She had breast cancer. Her consultant had advised her that she had a 25 per cent chance of remaining free from cancer in the next years, but a 57 per cent chance of dying. Initial trials of Herceptin had suggested considerable benefit in the kind of cancer Ms Rogers suffered from. Initially she paid for the drug herself, but when she lacked funds she asked her PCT to fund it. Their policy was only to fund the treatment where there were exceptional personal or clinical circumstances. They determined that there were none in her case.

The Court of Appeal held that the policy of only funding the drug in exceptional circumstances was legal only if the policy maker had envisaged what kind of cases would be exceptional. If in fact it was not possible to imagine such exceptional circumstances the policy was in fact one of complete refusal and this would be irrational, because it failed to take into account each individual case (*R v North Lancashire ex p G*\(^\text{109}\) was followed). The court found that the reality here was that among those patients for whom the drug would be appropriate there was no rational basis for distinguishing

110 According to Newdick (2007) this was because they had misunderstood statements made by the Secretary of State for Health who had stated that women should not be denied access to breast cancer treatment due to cost.

111 At para 77.

112 See also R (Gordon) v Bromley PCT [2006] EWHC 2462 at para 41 where care for young children was mentioned as a possible exceptional circumstance.


114 Newdick (2007: 244).

115 Foster (2007).

It is important to appreciate that it was central to the court’s reasoning that the Trust had declared that costs were not a relevant factor. The Court of Appeal appeared to conclude that if the PCT had openly said that budgetary considerations would be a factor in deciding whether the drug could be granted then it would be permissible to deny a patient the drug on the grounds of cost. The decision is not, then, a decision saying that cancer patients have a right to drugs which will help them. It is rather a decision that rationing decisions must be made openly. If the truth is that the PCT cannot afford to give the drug to a patient it must be open about the relevance of the cost issue. Interestingly Sir Anthony Clarke suggested that it might be appropriate in such a case to decide that a drug could be funded for a mother caring for a disabled son, but not a woman with no dependants.

A similar point can be made about R (Otley) v Barking & Dagenham NHS PCT in which Victoria Otley’s NHS Trust refused to fund a treatment using an anti-cancer drug (Avastin). She sought a judicial review of that decision. The decision not to fund her treatment was made by a panel of the Trust. The panel had received a report which recommended the drug in Ms Otley’s case. However a member of the panel noted that in research studies Avastin had not been used as part of a cocktail of drugs. On appeal it was held that the panel had failed to give sufficient weight to fact that this regime of drugs was the only set of drugs available. Although the chance that Avastin could lengthen her life by more than a few months was slim, this was an important chance that she should be allowed to have. The court emphasized that this was not a decision which had been made on the basis of scarce resources.

What is clear is that the courts are unlikely to find a particular rationing policy unlawful on the basis of it being unreasonable. An application is more likely to succeed where the complaint is essentially procedural: the proper reasons for the decision are not given, the policy was misapplied, or the applicant’s individual circumstances were not taken into account. Ironically this may mean it is far harder to challenge the decision of a Trust which boldly states: ‘we cannot afford your treatment—there are other needier patients’ than a trust who tries to hind behind a formula based on exceptional cases. Christopher Newdick thinks it is not difficult for a court to find a procedural flaw if it wants to allow an application. By contrast Charles Foster thinks it is now easy for a Trust to ensure they comply with the law. One way of reading the decisions of the courts in this
area is that they want Trusts to be completely honest and open about the rationing decisions that they make.\textsuperscript{116} If treatment cannot be afforded the Trust should say so and not hide behind clever rhetoric.

10.2.4 Should the courts be more interventionist?

Supporters of a conservative role for the courts will emphasize how the courts are ill equipped to make rationing decisions, not just because, arguably, they lack the skills, but more importantly because they lack the information. They will be aware of the situation of the applicant, but they will not know about the other patients needing treatment. As Christopher Newdick asks:

\begin{quote}
\textit{during litigation on behalf of an individual patient, who will speak for the large numbers of patients who are not party to the dispute but who may be affected by its outcome, and for those particular patients whose operations will have to be cancelled if someone else is treated first?}\textsuperscript{117}
\end{quote}

Bingham MR has made the point this way, in \textit{R v Cambridge Health Authority ex p B}:\textsuperscript{118}

\begin{quote}
I have no doubt that in a perfect world any treatment which a patient, or a patient’s family, sought would be provided if doctors were willing to give it, no matter how much it cost, particularly when a life was potentially at stake. It would, however, in my view, be shutting one’s eyes to the real world if the court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet. They cannot pay their nurses as much as they would like; they cannot provide all the treatments they would like; they cannot purchase all the extremely expensive medical equipment they would like; they cannot carry out all the research they would like; they cannot build all the hospitals and specialist units they would like. Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make.

Opponents will emphasize the rights of individuals to treatment, especially where it is life-saving treatment. Where life-saving treatment is being denied simply to say ‘it’s too expensive’ is too easy. The courts are entitled to know exactly why it is too expensive, exactly what would be lost if the treatment was provided. Only then can an effective protection of individual patients’ human rights be protected.

10.2.5 Human Rights Act 1998

A patient could seek to bring in aid her or his rights under the European Convention on Human Rights.\textsuperscript{119} This could either be as an aspect of a claim for judicial review, or a freestanding application under the Human Rights Act 1998, sections 6 and 7.\textsuperscript{120} There are four main articles that might be relied upon, although, as we will see, only rarely will

\begin{footnotesize}
\textsuperscript{116} See also \textit{R (Linda Gordon) v Bromley NHS Primary Care Trust [2006] EWHC 2462 (Admin)} where Ousley J complained that the trust had failed to make it clear why it was refusing treatment.
\textsuperscript{117} Newdick (2005: 99).
\textsuperscript{118} [1995] 1 WLR 898, at 906C.
\textsuperscript{119} MacLean (2001).
\textsuperscript{120} There is no right under common law to receive treatment: \textit{Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930.}
\end{footnotesize}
they provide the basis of a right to treatment:121

- **Article 2: the right to life.** A person seeking life-saving treatment under the NHS might claim that not to provide them with it would infringe their right to life. The difficulty with such an argument is that although article 2 does protect the right to life, this has not been interpreted to mean that a person is entitled to every form of medical treatment they need to keep alive.122 After all, in most cases it is likely that life-saving treatment is not being offered to person A in order to provide life-saving treatment to person B. In such a case it cannot be that both A and B’s article 2 rights entitle them to the treatment.

- **Article 3: protection from torture or inhuman or degrading treatment.** It might be argued by an applicant that not being provided treatment leaves that individual in such a state of health that she or he is suffering inhuman or degrading treatment. Such an argument also faces difficulties. Like article 2, article 3 does not entitle a person to all forms of treatment that might avoid degradation.123 However, if a patient in hospital was inadequately fed or washed and this caused the patient to suffer, for example, malnutrition or serious bed sores this might infringe article 3. It might be argued that although article 3 does not give an automatic right to treatment it at least gives a right to basic care. Of course article 3 only applies where the state of health of the individual is of sufficient seriousness to amount to inhuman or degrading treatment.124

- **Article 8: right to private life.** It might be argued that the right to respect for one’s private life could include a right to receive the treatment one wants.125 However, in *North West Lancashire v A D and G* it was held that article 8 could not be relied upon to found a right to receive treatment.126

- **Article 14: protection from discrimination.** This is perhaps potentially the most promising line of argument for an applicant who can claim that the allocation of resources has been discriminatory on the basis of grounds such as race, sex, or religious belief. It would, of course, be surprising if a health authority were to do that. But there are two categories of cases which deserve greater attention. The first is age. Article 14 does not list age as an unacceptable ground of discrimination, but the list of factors are seen only as examples. The courts have been willing to add, for example, sexual orientation. If age were added then a claim could be brought if a patient felt she or he was denied treatment that a younger person in her or his shoes would have had. The second is disability. Again this is not a factor mentioned in article 14, but the courts may be willing to add it in. Could it be said that a decision not to give a donated kidney to a child suffering from Down’s Syndrome who needed a kidney transplant, but to give it instead to a ‘healthy’ child, amounted to discriminatory conduct?

If age and disability discrimination were held to fall under article 14 then the key issue would be whether or not the decision was ‘objectively justifiable’, because if it was then the decision could not be challenged. A strong case for justification may be if the disability or age meant that the likely success of the treatment was less. If, for example, a

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121 Foster (2007).
122 Maclean (2000).
124 *R (on the application of Yvonne Watts) v Bedford Primary Care Trust and Secretary of State for Health* [2003] EWHC 2228.
125 Epstein (1997) fiercely rejects claims to a right to medical treatment.
126 [2000] 2 FCR 525. See also *R (on the application of Yvonne Watts) v Bedford Primary Care Trust and Secretary of State for Health* [2003] EWHC 2228.
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donated organ was not given to a 70-year-old but given to a young man on the basis that the 70-year-old was less likely to survive the transplantation procedure than the young man then that would provide a justification. We will consider issues surrounding age discrimination later in this chapter.

10.2.6 European Charter of Fundamental Rights

Under article 35 of the EU Charter of Fundamental Rights there is the following right:

Everyone has the right of access to preventative health care and the right to benefit from medical treatment under the conditions established by national laws and practices.

This leaves much to the discretion of individual countries to set the limits of this right.

10.2.7 Negligence

An action in negligence could be brought against a local authority if it was claimed that harm had been caused to a patient as a result of a negligently made rationing decision. One issue in such a claim would be whether in making resource allocations decisions the health authority owes a duty of care to patients. This will depend on whether it is just and reasonable to impose a duty of care on the public authority in question. The key case on this is DHSS v Kinnear\(^\text{127}\) where the plaintiff claimed to have suffered brain damage as a result of vaccinations. Justice Stuart-Smith drew a distinction between operational issues which could be the subject of a tortious claim and a policy decision which could not be challenged by the law of tort. So in this case the policy of encouraging vaccinations could not be challenged. However, an allegation that misleading advice had been given about the manner and circumstances in which vaccinations should be provided could be challenged in the courts. This makes it extremely unlikely that an action could succeed in negligence to challenge a decision about resource allocation. A greater chance of success might meet a claim that, having decided to allocate resources in a particular way, it implemented that decision ineffectively. Even then the courts might take the view that it would not be just and reasonable to impose a duty of care on local authorities given the availability of alternative complaint mechanisms available, and given the impact on the NHS of having to deal with a large number of claims.\(^\text{128}\)

A claim of negligence could be brought against the individual health care professional based on the fact she or he improperly rationed health care resources. A court, when considering whether an individual professional is negligent, is likely to take into account that rationing decisions are normally taken at a higher level than an individual doctor.\(^\text{129}\) However, a professional who decided not to offer a patient treatment based on a rationing ground which was in defiance of her or his NHS Trust’s guidelines might face a challenge on the basis of negligence.

\(^{128}\) X v Bedfordshire [1995] 3 All ER 353.
\(^{129}\) Witting (2000).
10.3 How does the NHS ration at present?

Successive governments have been adamant that there is no such thing as rationing within the NHS. Tony Blair himself has stated ‘if you are ill or injured there will be a National Health Service there to help; and access to it will be based on need and need alone’. However, as the Bristol Inquiry said:

Governments of the day have made claims for the NHS which were not capable of being met on the resources available. The public has been led to believe that the NHS could meet their legitimate needs, whereas it is patently clear that it could not. Healthcare professionals, doctors, nurses, managers, and others, have been caught between the growing disillusion of the public on the one hand and the tendency of governments to point to them as a scapegoat for a failing service on the other... The NHS was represented as a comprehensive service which met all the needs of the public. Patently it did not do so...

Whatever politicians may say it is clear that when deciding what treatment a patient should be given NHS Trusts and doctors themselves are influenced by the monetary restrictions facing the NHS. Even if not done explicitly, the limits on resources mean that some patients are denied treatment that might be clinically desirable. So where and how does rationing occur?

(i) The Government

At one level the amount of money allocated by the Treasury to the Department of Health, and the taxation levels set by the Government, play an important role in determining the amount of money the NHS has to use in offering treatments to patients.

(ii) Clinicians

Medical professionals themselves ration. Perhaps unconsciously, the decision may be made that the treatment is not ‘worth while’ for this patient, or she or he is not considered an urgent case. In fact, there is very little evidence about the way that ‘clinical’ decisions can in reality be rationing. It has been said that ‘deterrence, delay deflection, denial and dilution’ of care all play their part. Indeed financial incentives are offered to some front line staff to discourage ‘excessive’ use of NHS resources. The benefit to politicians of clinical judgment is that it:

renders the process of rationing as if it were politically invisible, by fragmenting it across space and time into individualised and private transactions between doctors and patients.

The result was that the NHS was able to maintain the fiction of meeting everyone’s needs.

(iii) NICE

The most overt way in which rationing decisions are made is through the guidance issued by NICE (the National Institute for Health and Clinical Excellence). This guidance can recommend that treatments are not made available or only made available to certain categories of patients within the NHS. We will look further at the work of this body below.

(iv) Waiting lists
Another significant means of restricting access to treatment is the waiting list. A patient is not denied treatment outright, but must wait. Many Trusts have systems where urgent cases can be speeded to the top of the list. Further, it is not uncommon for patients to be told of the delay under the NHS and then, if they are able to afford it, seek speedier treatment under the private health schemes.

10.4 National Institute for Health and Clinical Excellence (NICE)
In the past rationing was done informally and often in a hidden way. Individual doctors and health authorities would make decisions about what treatments were ‘appropriate’ for patients. These were often presented as clinical decisions about what was best for a patient, even if in fact the decision was solely, or partly, influenced by economic considerations.\(^{135}\) One of the consequences of this was that the availability of treatment differed widely in various parts of the country.\(^{136}\) This became known as the ‘postcode lottery’. It led to a growing sense of unease, with important decisions about the allocation of health care resources being made in private, without full information and little or no accountability.

It was partly as a result of these concerns that the National Institute for Health and Clinical Excellence (NICE) was created. The then Health Secretary stated that NICE ‘will help to bring order and rationality to a system that all too often has appeared arbitrary and unfair’.\(^{137}\) This body now plays an important role in the rationing of health care within the NHS. One of its primary roles is said to be as follows:

The Institute will promote clinical excellence and the effective use of available resources in the NHS through the development and dissemination of guidelines for the management of certain diseases or conditions, guidance on the appropriate use of particular interventions, audit methodologies and the dissemination of these to support frontline staff and patients.\(^{138}\)

The official role of NICE is to establish and set uniform standards regarding treatment across the NHS. It will determine the effectiveness and appropriateness of treatments being offered on the NHS. For example, if it is believed that a new drug will provide an effective treatment for a particular condition that drug will be examined by NICE, who will consider its effectiveness and cost in deciding whether to recommend that the drug be made available on the NHS, not available at all, or available only to a certain class of patients. When its advice is not to prescribe a particular drug on the grounds of its cost, in effect this is rationing. Of course, it is not quite this straightforward because NICE will be looking at all kinds of factors when considering whether to recommend a drug. The chair of NICE has listed factors that would be taken into account:\(^{139}\)

- The clinical needs of patients in relation to other available technologies: this is obviously an overriding issue, and the evidence base for clinical effectiveness is crucial.
- The NHS’s priorities: this is a relative, and not an absolute, criterion.
- The broad balance between benefits and costs: this incorporates both clinical and cost effectiveness.

\(^{135}\) Schmidt (2004).
\(^{137}\) Milburn (1999).
\(^{138}\) NICE (1999).
\(^{139}\) NICE (1999).
2 THE STRUCTURE OF THE NHS

- The potential impact on other NHS resources: this is particularly relevant where there are potential ‘knock on’ effects for other parts of the service.

- The encouragement of innovation.

- Guidance from ministers on the resources available but, he added, he had never received guidance from ministers on the resources available.

A decision not to recommend a drug or treatment will not be based on the straightforward argument, ‘it’s too expensive’, but rather on a complex combination of clinical and economic factors. In theory a drug company or individual could seek judicial review of a decision of NICE, but it is difficult to imagine the decision of such an august body concerning such a delicate and complex issue being found unreasonable.

NICE’s role in assessing new treatments involves a number of factors. The first is in determining the effectiveness of the new treatments. It appears to be generally accepted that NICE carries out this technical side of its job well, using experts in relevant fields to assess proposed treatments and emphasizing the importance of evidence-based medicine. The second is in calculating the cost-effectiveness of the products. It is in this regard that greater concerns have arisen.

It is, perhaps misleading to emphasize the role of NICE as rationing treatment. In fact there are far more instances of NICE recommending treatment than suggesting it should not be available. Indeed, as one commentator has pointed out, although NICE has received plaudits, these have not come from NHS Trusts grateful at the amount of money saved as a result of NICE’s work. Indeed this point highlights a real difficulty for NICE’s role. It considers whether or not to approve a particular drug or treatment in isolation. It has no way of knowing which treatments a Trust will have to stop providing in order to follow NICE guidance. The difficulty therefore is that NICE cannot know whether the treatments which Trusts might forgo are more efficient or effective than the ones it is promoting.

The exact status and effect of guidance issued by NICE is unclear. A number of questions arise, which are explored below.

10.4.1 Are NICE guidelines meant to be binding on Trusts or clinicians?

NICE has emphasized that what it issues is ‘guidance’ and therefore cannot be binding on particular health care professionals. It explains:

Once NICE publishes clinical guidance, health professionals and the organizations that employ them are expected to take it fully into account when deciding what treatments to give people. However, NICE guidance does not replace the knowledge and skills of individual health professionals who treat patients; it is still up to them to make decisions about a particular patient in consultation with the patient and/or their guardian or carer when appropriate.

140 NICE (2000).
141 In R v Secretary of State for Health ex p Pfizer [1999] Ll Rep Med 289 a successful challenge was made to the means by which the Secretary of State sought to ration the use of Viagra within the NHS. See Eisai v NICE [2007] EWHC 1941 (Admin) for a largely unsuccessful challenge.
142 Campbell (2003).
143 Harris (2007).
144 See Iqbal, Pryce, and Afza (2006) for a discussion of the ways that in practice, local priorities and NICE guidelines may be in tension.
That said, if a patient is refused treatment which has been recommended by NICE then the professional could face a claim of negligence unless she or he had strong reasons why the patient should not receive that treatment.

Since January 2002, NHS Trusts have been required to provide funding for medicines and treatments recommended by NICE and this is to be taken into account when general annual budgets are set out. However, making the money available and ensuring that NICE guidance is followed are not the same thing.146 As we shall see shortly, in fact it is clear that NICE guidance is not always followed by NHS Trusts.

What if the NICE guidelines recommend that a drug not be used, is that binding? In R v Secretary of State for Health ex p Pfizer147 it was held that Health Circular 1998/158 which stated that Viagra (sildenafil) should only be made available in exceptional circumstances in the NHS was unlawful. This was because it was seen as an improper interference in a doctor’s professional judgment.

10.4.2 Are Trusts in fact following NICE guidelines?

As already indicated, following NICE guidance is not mandatory. This has led to varying levels of compliance with NICE guidance among NHS Trusts.148 When the Audit Commission looked into the compliance with NICE guidance149 it found that 33 per cent of responding NHS bodies said that they had not been able to fund full compliance with NICE guidance. It found that NICE guidance was not integrated into financial planning decisions in a routine way. The Audit Commission concluded that it was not cost difficulties that prevented NICE guidance from being followed, but rather poor management.

10.4.3 To what extent is NICE meant to look at economics?

One of the complaints about the work of NICE is that it focuses on the cost-effectiveness of the drug or proposed treatment in the abstract and decides whether it provides good value for money.150 But being one step apart from the NHS Trusts it does not consider how the Trusts are to afford the implementation of the guidance. To be blunt if a new drug is approved by NICE and a Trust adopts that drug the money to pay for it must come from somewhere. NICE might reassure us that the drug is cost-effective, but it does not (of course) tell a Trust what it should cut from its expenditure when adopting the drug. This has led some to claim that the work of NICE has skewed priorities for Trusts. They are keen to follow NICE guidance but in so doing they may be cutting back on other equally valuable treatments that NICE is yet to consider.151 Of course NICE does consider the question of overall resource implication in the abstract. As Professor Rawlins, chair of NICE, put it:

The Institute will have to take into account the NHS’s broad clinical priorities and the broad balance between benefits and costs. The Institute will have to take into account guidance from Ministers on the resources likely to be available; and the Institute will have to ensure that the technology represents an effective use of available resources.152

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146 Syrett (2003).
147 (1999) 51 BMLR 189.
148 Eg, in relation to cancer, see National Audit Office (2005b).
NICE has also emphasized that it makes decisions about whether or not a treatment is cost-effective. It does not determine whether or not the treatment is affordable. That, it seems, is regarded as primarily an issue for the Government.\textsuperscript{153} It has been estimated that the first 22 treatments approved by NICE will have cost £200 million, around 0.5 per cent of the annual NHS spending.\textsuperscript{154} Not surprisingly there have been concerns that attempts to comply with NICE guidance is putting financial strains on Trusts.\textsuperscript{155}

10.4.4 What is the relationship between NICE and the Government?

The exact relationship between the Government and NICE is delicate. On the one hand NICE can be convenient for the Government. When NICE decides not to approve a new expensive drug for a particular illness the ‘flack’ is directed towards NICE, rather than the Government. Indeed it has been suggested that the creation of NICE is part of a strategy of blame avoidance and blame diffusion within the NHS.\textsuperscript{156} However on occasion the Government will want to appear to be taking an active approach to a health problem. Hence we saw, in August 2005, NICE being ordered by a government minister to fast track an assessment of Herceptin, a drug designed to treat breast cancer,\textsuperscript{157} and in 2002 the Government’s announcement that it would provide a form of funding for a drug to treat Multiple Sclerosis, despite NICE’s original decision that it was not cost effective.\textsuperscript{158}

In relation to fertility treatment, although NICE recommended three cycles, the Department of Health has stated that Trusts are only required to offer one, while they work towards meeting the NICE guidance. As no deadline has been issued for meeting the NICE guidance it could be argued that the Department has substituted its own view for that of NICE.\textsuperscript{159}

NICE, however, insists that it is free from Government intervention and pressure from industry.\textsuperscript{160} However the success of campaigns by manufacturers (eg Glaxo-Wellcome on zanamivir) and pressure groups (the Multiple Sclerosis Society on beta-interferon and glatiramer acetate), causing a reversal of an initial decision by NICE, has indicated to some commentators that NICE is not immune from outside pressure.\textsuperscript{161} Significantly the Bristol Infirmary Inquiry suggested that NICE be kept clearly separate from the Department of Health.\textsuperscript{162} However, NICE itself believes that its status as an NHS body helps give it legitimacy.\textsuperscript{163}

10.4.5 How transparent is NICE?

There have been concerns expressed that the process by which NICE makes guidance lacks transparency.\textsuperscript{164} In particular there are concerns from patient groups that it is unclear how their representations are taken into account and precisely what factors NICE is using to make its decisions.\textsuperscript{165} That said, the NICE website\textsuperscript{166} is replete with policies, procedures, and decisions, and it has a ‘communication strategy’ to ensure it
communicates effectively with stakeholders. Despite this there appears to be an unwillingness to accept that the decision-making process is as transparent as it appears. In part the lack of confidence that some have in NICE may be due to the fact that NICE (perhaps inevitably) must conclude that a medicine either is or is not effective, when in reality the issue is far more complex than that. As Smith suggests, NICE’s problems are down to its willingness:

to give the impression that if the evidence supports a treatment then it’s made available and if it doesn’t it isn’t. In other words, the whole messy problem of deciding which interventions to make available can be decided with some data and a computer. It’s a technical problem. This lie corrupts the concept of evidence-based medicine… The evidence supports decision-making, but the evidence can’t make the decision. The values of the patient or the community must be part of the decision.167

One way NICE has sought to respond to such concerns is to make greater use of the Partners’ Councils which seek to represent the views of the general public. The difficulty is that the more weight that is given to the views of the general public the less weight NICE’s guidance will carry as an in-depth independent scientific assessment on the effectiveness of medicine.

10.4.6 How does NICE decide whether a treatment is cost effective?

NICE in assessing cost-effectiveness places much weight on quality adjusted life years (QALY). This is a very popular way of deciding how medical treatments should be rationed. We will consider this concept in more detail shortly when we consider how health care services should be rationed.

10.5 How should health care be rationed?

Ethicists interested in this area enjoy conundrums of this kind:

**TO PONDER**

There are three patients in your care. There is only enough money available to fund one of them. Which will you fund?

(i) Alf is a newborn. He has a serious disability and needs intensive care to be kept alive. The likelihood of him surviving into his twenties is moderate and even if he does he will be seriously disabled. Without the treatment he will die.

(ii) Steve is a student who is suffering serious liver failure following excessive drinking for many years. A liver transplant and further treatment is required. If successful, and if he gives up drinking, there is no reason why he should not expect to have a normal life expectancy. Without the treatment he will die.

(iii) Wendy is young mother caring for two toddlers. She has developed a form of cancer. With the treatment it is estimated she will live another ten years, without the treatment she will die a painful death within the next few months.

Of course, it is rare that choices facing medical professionals are so stark but the discussion of such hypotheticals helps to bring out some of the key issues. Below are some possible responses to them.

10.5.1 ‘Treat all of them’

To most people the initial response to a hypothetical scenario such as those outlined above is that we should fund all of their treatment. What sort of a society do we live in if we cannot provide treatment to all of these people? Those tempted by such a response might suggest that we need to determine what kind of health service is the minimally decent we would want and to set taxation accordingly. If people realize that without higher taxation people would die they would pay. It is, of course, not that straightforward. What this point emphasizes, however, is that at the end of the day if rationing decisions produce unacceptable results, the answer may be to increase funding for the NHS, rather than try and tweak further the rationing system.

10.5.2 ‘There is no answer’

An acceptable answer to these dilemmas is that there is no correct answer. A perfectly legitimate case can be made for Alf, Steve, and Wendy. All we can ask of the health service is that the way these decisions are made should be open, accessible, and there is a means of challenging any decision made. Although these values are important many people would not find it acceptable if the NHS funded cosmetic surgery but not cancer treatment, however open, accessible, and open to review the system was. It may be correct there is no ‘right’ answer, but that does not mean there are no ‘wrong’ answers.

10.5.3 A rights perspective

To some we have a human right to a minimally decent standard of health care and that would include providing life saving treatment. Alf, Steve, and Wendy all have a right to receive treatment. Of course where the treatment is not life-saving there may either be no right to it at all, or the rights of individuals will need to be pitted against each other. This perspective has resonance in a legal age focused on rights. However, it does not really provide an answer to the difficult questions. If in our scenario there simply is not enough money, how are these rights to life to be weighed? And in the case of non-life-threatening conditions, a rights approach, without more, does little to indicate how the rights in question are to be balanced. So we need something more to assist us in balancing rights.

10.5.4 Need

Another ‘simple’ solution is to base rationing on the basis of need: resources should go to the patient who needs them most. But this leaves open the question of need, which of Alf, Steven, and Wendy is in greater need? We need a more sophisticated concept than ‘need’ to help us.

10.5.5 QALY

Quality Adjusted Life Years (QALY) is probably the most popular way of analysing the cost-effectiveness of treatments and is widely used in decision-making in rationing. It is

\[\text{168 Smith II (2002).} \quad \text{169 NHS Management Executive (1991).} \]
used by NICE,\textsuperscript{170} and therefore we shall pay particular attention to this concept. QALY, as used in rationing decisions requires an assessment of three factors:

- How many years extra life will the treatment provide this patient?
- What will the quality of those extra years be?
- How expensive is the treatment?

A treatment that provides a year of perfect health scores as one; however, a year of less than perfect health will score less than one. Death is equivalent to zero. In some schemes is it possible to have a state of health worse than death and this may achieve a negative score. Under QALY, therefore, a treatment which provided a patient with an extra year of perfect health would be preferred to a treatment which provided a patient with an extra year, but a year of pain and low life quality. A treatment which offered a large number of QALY for a small amount of money would be highly cost effective, while one that produced a low number of QALY for a large amount of money would not be.

Someone required to ration health services can therefore examine a range of different services and consider how many QALY for how much money is offered. The following figures have been suggested in one book as the cost per QALY:\textsuperscript{171}

<table>
<thead>
<tr>
<th>Service</th>
<th>Cost per QALY (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital dialysis for end-stage renal disease for patients aged 55–64 years (compared with no treatment)</td>
<td>45,000</td>
</tr>
<tr>
<td>Coronary artery bypass graft for patients with mild angina (compared with medical management)</td>
<td>26,000</td>
</tr>
<tr>
<td>Breast cancer screening programme</td>
<td>6,800</td>
</tr>
<tr>
<td>Cervical cancer screening (women aged 20–59 years)</td>
<td>200</td>
</tr>
</tbody>
</table>

The main benefit of QALY is its ability to provide a way of considering not only the length of time that a patient gains, but also the quality of that life. It provides a unit which enables those at the policy level to compare contrasting treatments for a particular medical condition. Clearly in considering alternative treatments for, say, back pain, a Trust will be attracted to using that treatment which offers the lowest cost for each QALY. It also provides a way of comparing different treatments for different conditions where a health service is having to choose between funding them.

How do NICE use QALYs? Professor Rawlins, chair of NICE in 2002, argued that if the QALY value was over the range £25,000–£35,000 there needed to be special reasons for regarding the treatment as cost effective.\textsuperscript{172} He gave as examples of special reasons: particular features of the condition, wider societal costs and benefits, and the innovative nature of the technology.

### 10.5.6 Problems with QALY

The use of QALY has not proved uncontroversial. Here are some of the objections that are made:

(i) One objection to the use of QALY is the difficulty in the calculation. How is it possible to assess the quality of a person’s life?\textsuperscript{173} How can you compare being confined...
to a wheelchair to being blind? Is it really possible to put a figure on such things? The difficulty is that what gives our lives quality differs greatly from person to person. If a person loses the use of a finger and a treatment is available which could restore its use how do we assess the added quality of restoring use of a finger? For some people the loss of use of a finger will matter very little, to another, a musician for example, it might hugely affect their quality of life. An attempt could be made to assess an average improvement in quality of life but this could be complex. How are we to assess the improvement in quality of life produced by cosmetic surgery? In one quality-of-life study, a group of persons who won the lottery had similar quality-of-life ratings one year after winning as did a group of persons who had become paraplegic. Can anyone really know how bad certain conditions are if they do not suffer from them?

(ii) The QALY approach can produce unacceptable results. In particular it places no weight on concepts such as dignity. A severely mentally ill person with no real awareness of what is happening to them could be left in appalling circumstances on the basis that to offer them basic care would not improve their quality of life, because they lack awareness of their condition.

(iii) A particular concern is that QALY works harshly against older people. An older person who has a low life expectancy will find it much harder, if not impossible, to show a higher number of QALY than a younger person if facing a similar illness. Indeed they are unlikely to be able to compete with a child with a much less serious illness. There are also concerns that there are difficulties in that it may work against people who are seriously ill, for whom all treatment can offer is a slight increase of life expectancy or a small increase in pleasure.

There is also a danger that it draws no distinction between giving one person 40 QALY and four people 10 QALY. It has been therefore described by John Harris as a ‘life-threatening device’ in that it prefers life years over individual lives. Some have argued that taking age into account in effect amounts to age discrimination. There are two responses that supporters make to this kind of argument.

First, it may be that it is age discrimination, but that is perfectly acceptable. Surely most people would agree that, if we had no choice but to save the life of ten eight-year-olds or ten 80-year-olds we should prefer the former option. Was not the death of the Queen Mother, although sad, far less of a tragedy than the death of the much younger Lady Diana? There must be few grandparents who, faced with the awful alternative of either dying themselves or have their grandchild die, would not think it preferable that they were the ones to go. Any age discrimination might be justified on the basis of an argument that the loss to the 80-year-old of the short period of life is less than the loss of many years for the young person. The discrimination is not on grounds of age but on an assessment of the loss for the individual.

A second response might be to deny that there is age discrimination here. In a QALY approach the distinction is not based on age as such but rather the number of future years a person is predicted to live. QALY draws no distinction between a 20-year-old with a terminal illness and short life expectancy and an 80-year-old with the same illness and life expectancy. Indeed this has even led one commentator to suggest that the

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176 Brickman and Coates (1978).
177 Goodl (1996).
178 Harris (1987).
179 Keown (2002).
181 Shaw (1994).
QALY is ‘not ageist enough’\footnote{Lockwood (1988).} because we should in the example given prefer giving a 20-year-old a few extra months, rather than the 80-year-old.

Note, however, that no distinction on age would arise if treatment is on-going (eg the taking of medication). This is because although a younger person taking the medication would live for longer than the older person taking the medication, the costs of medicating the younger would be proportionately much higher.

There is less dispute over cases where age is deemed relevant because it impacts on the likely success of any treatment.

Opponents of age as a relevant factor argue that it is simply unjust to value the life of an older person as being of less value than the life of a younger person: both lives are equally precious. The use of age reinforces the all too common perception in our society that the elderly are a ‘waste of space’. We must respect and value old age and this means offering the same treatment we would to a younger person. John Harris has argued that age offers an utterly arbitrary criterion. As he points out if there is a fire in a lecture theatre do we really think we should try and get the 19-year-olds out before the 20-year-olds?\footnote{Quigley (2007b: 465).}

NICE has made it clear that ‘health should not be valued more highly in some age groups than others’ but that ‘where age is an indicator of benefit or risk, age discrimination is appropriate’.\footnote{NICE (2005a).}

(iv) It has been argued that QALY will work against the interests of the disabled.\footnote{Herring (2008).} If two people who suffer from a condition are being considered and one has a disability and the other has not, it is arguable that the impact of the treatment on the non-disabled person will be greater because it will restore them to full health, and therefore their QALY will be higher. For example, it has been claimed that in deciding who should receive donated hearts Down’s Syndrome children have been overlooked in favour of ‘normal’ children.\footnote{Savulescu (2001b).} There are many to whom that is unacceptable, but it could be said to be justified on a QALY basis if Down’s Syndrome children are thought to have a lower quality of life than other children.

(v) It might be argued that QALY is too individualistic in focusing just on the impact of the treatment on the individual patient.\footnote{Herring (1987) and Harris (2001).} When considering a patient the improvement in the patient’s quality of life alone is considered and the impact on their carers counts for nothing. It may be that, for example, a drug which prevents incontinence might not hugely improve the quality of life for the patient, but have a dramatic impact on the quality of life for their carer. Others strongly object to arguments of this kind. If we start to take into account not only the individual patient but all those they care for, the task of comparing treatments would become highly complex.

(vi) It has been claimed that QALY inevitably cause us to weigh up the worth of different people, something that is ethically inappropriate. Muireann Quigley\footnote{Quigley (2007b: 465).} argues:

If I need to decide whether to give a treatment to either patient A or patient B and I utilise the QALY, then I am effectively balancing the improvement (or deterioration) in the quality of A’s life multiplied by the number of life-years he gains (or loses) against the same calculation for B. The best score will determine which person will be the most cost effective to treat from my limited resources. Unfortunately, what we are doing when we
engage in this type of calculation, in particular, is making value judgements about the lives of those two patients (identifiable or not), because the result is that their lives and health are given lower priority.

Others disagree and insist that QALYs are contrasting treatments, rather than people. Even if Quigley is correct, it may be that the weighing up of the value of the lives of patients is an inevitable part of rationing, rather than being a unique aspect of QALYs.

NICE, in making its guidance will take into account the QALY of treatments. It has been suggested that treatment which costs more than £30,000 per QALY will not be approved, although NICE has denied there is such a strict cut off. Its guidance suggests that above £30,000 per QALY the case has to be ‘increasingly strong’ if the treatment is to be approved. In respect of one cancer drug, NICE approved its use after the manufacturer said that the NHS would be refunded in cases where the drug did not benefit a patient. Such deals will increase the cost-effectiveness of some drugs.

10.5.7 Daniel Callahan

Daniel Callahan has recommended an approach which suggests that we need to provide for each person a fair rationing of health care across their lives. He suggests that our society has become obsessed with avoiding death and that we need to find again the notion of an acceptable death. There comes a point in people’s lives when death should be regarded as an acceptable event. At that point the use of health care resources to assist such a person to keep on living should not be used. This might be in one’s late 70s or early 80s. If people were to choose whether they would rather have money spent on them if they fell ill when young or when old they would prefer to have the treatment they needed when young. Another author with a similar approach has suggested that there comes a point where a person has had a ‘fair innings’, and it is right to focus health care resources on those who have been unlucky enough to face the possibility of not having a normal life span, rather than those who have already had such a life.

His proposal has proved highly controversial. Although Callahan appears to believe his proposal would solve the funding crises facing health care it should be pointed out that, even if only very limited health care was offered to those over 80, it is unlikely that it would resolve our rationing problems, the savings by doing that would not be sufficient. One objection to his approach is that it proposes one particular view of life: an active youth and middle age, followed by an old age of little worth. Many people may regard life like that, but many don’t. Many look forward to old age as a time of rest and respect. In other words he imposes on everyone one particular vision of how to live a life on everyone, and it is one that many people feel does not show a sufficient respect for old age. It has also been pointed out that the proposal is likely to work against the interests of women, as a far higher percentage of women than men reach the age of 80.

190 Claxton and Culyer (2006)
192 NICE (2002b); Kmietowicz (2001). Raftery (2001) notes an exception to this rule for treatment of motor neurone disease, which had a cost per QALY of £34,000–£44,000.
193 NICE (2002b).
194 NICE (2004b: 6.2.6.1 and 6.2.1) although some commentators suggest that in fact looking at their decisions it appears to be closer to £35,000–40,000 (Devlin and Parkin (2003)).
195 BBC Newsonline (3 June 2007).
197 Callahan (1990a).
198 Daniel Callahan has recommended an approach which suggests that we need to provide for each person a fair rationing of health care across their lives.
200 Dixon (1994).
10.5.8 Equality of treatment

John Harris argues that each citizen has an equal claim to having her or his individual health needs met. Those who are old or disabled or have a poor prognosis of health have no less a right to health services than anyone else. The primary goal, he argues, must be to save lives. He thinks it utterly wrong that the life of an ill and expensive-to-treat person could be sacrificed under a QALY scheme to improve, by a small amount, the health of a large number of young healthy people. He argues:

The principal objective of the NHS should be to protect the life and health of each citizen impartially and to offer beneficial health care on the basis of individual need, so that each has an equal chance of flourishing to the extent that their personal health status permits.

Where it is not possible to save everyone’s life with the resources available he recommends allocation should be decided by a lottery and in that way there is no suggestion that one person’s life is regarded as more valuable than that of another.

This approach, based on equality of access, appears to reject even placing weight on the likelihood of success of treatment. That appears counter-intuitive. To allocate a scarce organ to a person for whom it is likely to fail when there are others needing the organ who have a good chance of thriving with it seems difficult to justify. Critics argue that this could lead simply to a squandering of resources. To provide treatments to those with only a few months to live and deny the same treatment to a person with many years of life ahead of them is likely to increase social costs and costs for the NHS.

10.5.9 Rawlsian approach

John Rawls’ ‘original position’ approach has been advocated by some as a solution to the rationing dilemma. His approach involves a ‘thought experiment’ in which free and equal citizens negotiate about the world in which they are to live. They have a ‘veil of ignorance’, meaning that they do not know what kind of life they will have or what position they will be in. How would they decide how health resources should be allocated? Would they agree that young people should have a primary call on resources, fearing that they may appear in the world as a young person with a serious medical condition?

This is an attractive way of considering the problem. However there are difficulties with it. As already mentioned it is extremely difficult for such a negotiation to take place without a full knowledge of what suffering from various treatments would be like. How can this hypothetical group decide whether money is better spent providing treatments for arthritis or depression without having experienced the conditions? In any event predicting how people in the thought experiment would decide to ration treatment is problematic.

10.5.10 Asking the general public

One solution to the difficulties facing rationing would be to fall back on democracy. Should we simply obtain the views of the general public and follow their assessments as

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201 Harris (1997) and Harris (2005c). See Claxton and Culyer (2006) for a powerful rejoinder to Harris’s views.


204 Daniels (1985) thinks it would.

205 Nord (1999); Cookson and Dolan (1999).
to how priorities in the NHS should be ranked? Notably NICE seeks the views of the general public through its Citizens’ Councils when setting their guidance. The rather limited surveys that have been carried out do provide some clear messages: the young should be given priority over the old; those with dependants (e.g. children) preferred over those without; and those who have looked after their own health should be given higher priority than those who have not.

There are, however, grave concerns about putting too much weight on public surveys of this kind. Can members of the public really understand what it is like to suffer from multiple sclerosis, infertility, or gender identity dysphoria, for example, without personal experience? There is a concern that prejudice, rather than reason will dominate some of the decisions.

10.5.11 Oregon

Much attention has been paid to the rationing system developed in Oregon for Medicaid, in the United States. The basis of the scheme could be found in the Basic Health Services Act 1989. The Act created the Oregon Health Services Commission which ranked services that would constitute the decent minimum coverage. The ranking was determined by questioning citizens to consider which treatments were seen as having greater social value. The goal was to fund as many of these priority services as possible. The Commission produced a list of procedures based on quality of wellbeing after treatment and cost effectiveness. The list was controversial and produced some results that appeared arbitrary. The initial list contained 709 treatments, although this has increased over time. They were ranked according to the benefits to the population. Having established the ranking the funds available were allocated to the treatment starting with those at the top of the list. It was found that only the first 587 treatments were available. All treatments lower on the list were not available.

Of course the list is highly controversial and inevitably some people would argue that some things should be higher than others on the list. The first list produced treatment for thumb sucking and tooth capping as having higher priority than for ectopic pregnancy, cystic fibrosis, AIDS, and appendectomy. Other difficulties arose in that, if a patient was suffering from a number of illnesses which, combined, posed a serious risk to her or his well-being, but all of them fell below the cut off point no treatment could be offered. It was therefore said by some to be too strict a restriction on clinical judgment.

The scheme was arranged to enable all eligible people needing treatment to receive procedures as far down the list as possible given the budget set for health care. It faced difficulties in that the number of people eligible to receive treatment exceeded expectation. The scheme was designed to deal with pressure on the budget by reducing the treatments available, rather than reducing the number of people eligible. However, a dramatic increase in the number eligible meant that there needed to be a change in the

206 Davies (2005) examines their work.
209 For the latest proposal in relation to the scheme see Oregon Health Services Commission (2007).
212 See Newdick (2005: Chap 8) for a useful discussion.
10.5.12 Patient choice

One interesting option is to seek to develop a range of schemes of rationing and allow patients to select the scheme that they prefer. So, the arrangement may be that at 18 you must choose from a variety of options. If you are not concerned about being denied treatment in old age you may opt to be part of a scheme in which rationing decisions do take account of age. If, on the other hand, you wanted a scheme under which every effort was made to postpone death even in old age, you may prefer to opt for a scheme that is willing to invest money in treatments at the end of life. The difficulties with such a proposal are that people will need to make the choice without sufficient information available to them. There would also be difficulties with the treatment of children, but they could be exempt from the scheme.

Waste in the NHS

With all the talk of rationing it is important to find waste in the NHS (Chief Medical Officer (2006b)). Like all large organizations cynical critics can find mystifying examples of wastefulness in the NHS:

- Terence Hope, a brain surgeon, was suspended on full pay of £80,000 a year after being accused of not paying for an extra helping of soup at the canteen at Queen’s Medical Centre, Nottingham, in 2004. He claimed he was only collecting some extra croutons. His suspension was to enable a full investigation to take place. Several operations had to be postponed.
- In 2003 a lap dancer earning £500 a night was given cosmetic breast surgery on the NHS. This was justified on the basis that she was suffering from depression.
- The NHS spent £40,000 on a ‘patient experience definition’ of what makes a good experience for a patient. The result explained that the sick want to get better. As Lib Dem health spokesman Paul Burstow said, ‘Taxpayers will find it difficult to understand why £40,000 has been spent on common-sense definitions.’
- In 2005 the Serious Fraud Squad (Guardian (2005)) started an investigation into companies which may have defrauded the NHS of hundreds of millions of pounds.
- In 2006 it has been claimed that the NHS spent £172 million on external management consultants (BBC Newsonline 12 September 2006).

10.6 Controversies over rationing

10.6.1 Drawing a distinction between treatment for ill health and life style enhancement

To some rationing in the NHS would be easier if a clear distinction was drawn between treatment for ill-health and ‘life-style enhancement’. It is argued that is not the job...
of the NHS to make people happier, but just to improve ill health.\textsuperscript{218} Hence, even if cosmetic surgery makes people happier it should not be available on the NHS because it is not curing an illness. More controversial examples may be: not providing gender reassignment surgery, obesity treatment, or treatment for erectile problems on the NHS. However, as these examples demonstrate, the line between treatment and enhancement is not easy to draw. The Court of Appeal in \textit{R v NW Lancashire HA ex p A}\textsuperscript{219} explained that gender reassignment surgery is an effective treatment for a recognized medical condition. The better view is that far from being a ‘lifestyle choice’ the surgery is needed to treat a genuine medical condition.

\textbf{10.6.2 The Hippocratic Oath}

It has been suggested that there is a tension between the obligation a doctor has under the Hippocratic Oath and the concept of rationing.\textsuperscript{220} Under the Hippocratic Oath doctors promise:

\begin{quote}
I will follow that system of regimen which, according to my ability and judgment, I consider for the benefit of my patients.
\end{quote}

But how does a doctor do that if the rationing system in place means that she or he is not permitted to provide the best treatment? It may be that in this regard the Hippocratic Oath is outdated. The GMC guidance is notably more cautious, stating that doctors ‘provide effective treatments based on the best available evidence but also requiring them to ‘make efficient use of the resources available’.\textsuperscript{221} As this indicates, with limited health resources it simply is not always possible to give every patient the best available treatment. If that is inconsistent with the Hippocratic Oath then it needs updating.

\textbf{10.6.3 Rationing and ‘clinical judgment’}

One of the objections that has been made about NICE is that it attacks medical professionals’ clinical judgment. In telling them when a treatment is appropriate this challenges the assessment of the professional as to the best treatment available to the patient. As we have seen, NICE insists that its guidance is not meant to restrict the freedom of doctors in individual cases, although it would be a brave doctor who departed from the guidance without a ‘reasonable justification’.\textsuperscript{222} Christopher Newdick has argued that we need to be wary about the term ‘clinical judgment’. He looks at the rates of hysterectomies per 100,000 population in various countries and finds the following: US—700; Canada—600; UK—250; and Norway—110. He argues that the difference in these rates cannot be put down to ‘clinical judgment’ in particular cases. The figures ‘call out for an explanation’. They certainly suggest that either, in some countries some women are receiving unnecessary hysterectomies, or that in others they are not receiving them when they are required. Saying that something is clinically required may, therefore, reflect as much a social judgment as a medical one.

\textsuperscript{218} Gilbert, Walley, and New (2000).
\textsuperscript{219} [2000] 2 FCR 525.
\textsuperscript{220} Newdick (2005: 17).
\textsuperscript{221} GMC (2007).
\textsuperscript{222} See Bristol Infirmary Inquiry (2001: 30) which suggested retraining may be needed for professionals who regularly breach NICE guidance without a reasonable justification.
10.6.4 *Fault of the patient?*

It has been estimated that in the developed world a third of all diseases can be attributed to a ‘lifestyle choice’ involving: tobacco, alcohol, blood pressure, cholesterol, and obesity. In making a rationing decision should we draw any distinction based on whether a patient has brought about the condition upon themselves? Should we be more willing to give treatment for heart disease to a patient who has caused her or his condition by smoking, than to one who bears no responsibility? If a doctor arrives at the scene of a car crash and there are two patients both of whom urgently need her or his attention should she or he focus on the innocent pedestrian rather than the drunk driver? Many people instinctively feel that an ‘innocent’ patient deserves preferential treatment as regards the ‘blameworthy’ treatment in rationing decisions.

The difficulty is in deciding the extent to which someone can be blamed for their condition. Is a lawyer who suffers a cardiac disorder due to overwork and stress to be blamed for not having a more sensible work–life balance? Is a firefighter who suffers an injury while putting out a blaze to be blamed for taking on such a risky occupation? The difficulties in making these kinds of assessments have caused the GMC to argue: ‘You must not refuse or delay treatment because you believe that patients’ actions have contributed to their condition’. NICE states that an injury or illness being self-inflicted should not be a reason for denying treatment, but it can be taken into account in deciding whether treatment will be effective. But others argue that if we acknowledge a right to health care with that should come responsibilities to take care of your health. It is possible, through your irresponsible actions, to forfeit your right to health care. An alternative response to someone sympathetic to these arguments is to say that we should tax ‘dangerous’ activities such as smoking or drinking and use the revenue to treat the illnesses caused. In that case the cost incurred by the dangerous activity is shared among all those who engage in it and not just those who are ‘unlucky’ enough to fall ill. Alan Cribb argues that we need to develop a network of health obligations which are connected to entitlements.

It is generally accepted that there is a legitimate way in which prior fault can be relevant in a rationing decision, and that is where it might affect the effectiveness of a treatment. A heavy drinker who requires liver treatment, but is unwilling to cease drinking, may be denied treatment on the basis that the treatment is unlikely to be effective. This is the line NICE has taken: that ‘prior fault’ should not be relevant, unless it affects the future effectiveness of the treatment.

10.6.5 *Is the contribution a patient can or will make to society relevant?*

In allocating health care resources, is it appropriate to consider the contribution a person has or will make to society? If the choice is between offering treatment to a middle aged leading scientist who has made a major breakthrough in research into the treatment of cancer, or a person who is long-term unemployed, should those factors be taken

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223 For discussions of this issue see Cappelen and Norheim (2005); and Underwood and Bailey (1993).
226 NICE (2005a: principle 10). For criticism of this approach see Holm (2006) who asks if sports people should not be allowed to have surgery as they are likely to continue playing sport and impede their recovery.
227 Cappelen and Norheim (2005).
228 Cribb (2005: Chap 6).
229 NICE (2005a).
into account? Or what about the fact that one patient has young children to care for, who will be devastated by her death, and another is a single person with no dependents? The general view seems to be that these are not factors that can legitimately be taken into account. NICE has made it clear that social class or position in life should not be a relevant factor in deciding what treatment should be offered. To start to consider whether a patient is more worthy than another is to open a Pandora’s box of complex issues and will inevitably lead to claims of improper discrimination. On the other hand, simply to consider the cost-benefit analysis of treatment in terms of the individuals, and without a consideration of the wider interests of the community and those with whom they are in relationships, might be said to take an improperly individualist view of the world.

10.6.6 Gender
Of course, there is near universal agreement that it would be improper in the allocation of health care resources that sex should be a relevant categorization. However, as has been pointed out, using age as a category is in effect a form of sex discrimination as among the very elderly there are far more women than men.

It has also been argued that the individualist approach of QALY, focusing on the impact of treatment on the patient, without a consideration of the effect of a rationing decision on a carer, works against the interests of women, who undertake the majority of caring work.

10.6.7 The many or the few?
Imagine that we have a patient who is in urgent need of medical treatment without which she or he will die. The treatment will cost half a million pounds. The same money could be used to institute a screening process for cholesterol problems which, it is predicted, will save ten lives. If the choice must be made between the two, which is to be preferred? A QALY approach would prefer the screening programmes because for the same amount of money a large number of lives would be saved. Yet in fact within the NHS large sums of money are spent to save an individual’s life, at the expense of preventative health campaigns. It is not just in the NHS where this occurs. Large sums are willingly spent in a bid to rescue a sailor lost at sea or a miner trapped in a mine, whereas similar sums are not available to institute road safety measures which might save a larger number of lives. To some this is illogical. These decisions are based on emotion: we see the face of the person who needs the treatment, or the lost sailor, but we do not know the identity of those whose lives will be saved by the screening campaign or the road safety campaign. We feel compelled to rescue those whose identity we know about, and feel no compassion for the unidentified others who will die without the preventative steps. But many argue that is wrong and we should feel just as strongly about those unknown number of people whose lives are lost through a failure to fund a preventative illness campaign as we do about those we see in desperate need.

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230 NICE (2005a).
233 Hope (2005: Chap 3).
NICE’s controversies

The World Health Organization found that NICE was far less conservative in recommending treatments than similar organizations in Canada, Australia, the Netherlands, and Italy (WHO (2003)). However, this has not stopped there being outcries about some of NICE’s decisions. Here are a selection.

- In 2001 NICE considered a group of drugs used in the treatment of patients suffering Alzheimer’s disease. It recommended their use for a specific group of sufferers. In March 2005 it published an appraisal document looking at the effectiveness and cost-effectiveness of the drugs. The appraisal recommends that none of these drugs should be used, although patients already receiving one of the drugs ‘…may be continued on therapy…until it is considered appropriate to stop’ (NICE (2005): 1.3). Predictably this caused an outraged response among patients, carers, and professionals (Holm (2005)). The reasoning behind NICE’s preliminary conclusions were essentially economical. The cost per QALY for the drug was £40,000–£50,000. Holm (2005) argues that NICE’s approach in respect of these drugs has failed to give sufficient weight to the impact on a spouse or partner caring for someone with Alzheimer’s. Further anger greeted the announcement in July 2005 that NICE would need further time to consider the question of these drugs. A judicial challenge to the NICE ruling failed (Eisai v NICE [2007] EWHC 1941 (Admin)).

- In June 2000 NICE recommended that the drug Beta Interferon should be given to every patient with multiple sclerosis. This was in response to pressure from patients after initially recommending the drug not be used.

- In 2002 a decision was made to limit the number of drugs available for treating people with advanced colorectal cancer.

- In 2005 a new drug (Xeloda) became available for the treatment of bowel cancer. Although the drug was being used in Scotland, NICE stated it would not be able to consider it until May 2006, over a year later (BBC Newsonline 9 August 2005).

- In August 2002, NICE came under fire again after it recommended that the drug Glivec should only be given to a handful of patients with leukaemia. It later changed its mind.

11 Improving quality: targets

One of the main ways that the Government has sought to improve the services provided by the NHS has been through the use of targets. A huge range of issues from reducing suicide rates to waiting times has been subject to targets. Great pressure is placed upon NHS bodies to meet these. Where they are met the Government naturally seeks to claim credit for a very tangible benefit of the extra funding it has put into the NHS. We will not here consider in detail what these targets are or the extent to which they have or have not been met. Rather we shall look briefly at whether targets are a useful way of improving the quality of NHS performance.

The use of targets does provide a very concrete measure of improvement. Without them politicians may fear that the money given to the NHS will go into a ‘black hole’,
and there will be no measure of improvement to which politicians can point and say: ‘that outcome has resulted from the improvements we have made’. Of course, where, for example, patients have received treatment more quickly because of waiting list targets, the patient benefits.

There are, however, concerns over the use of targets. The Audit Commission emphasizes that targets must be ‘the means not the end’.237 The danger with targets is that the obsession becomes being able to fill in the form at the end of the day saying that the target has been reached, rather than actually improving the service offered. It has been found that some Trusts have found ways of technically meeting waiting list targets (eg by cancelling operation appointments on the day in question) which have ended up harming patients, even if appearing to meet the targets.238 There is also a concern that targets can obscure the real priorities of the NHS. There is a concern that management cultures can become obsessed with meeting targets and overlook the real goals of the NHS.239 In particular there is a concern that aspects of the NHS for which there are not targets can be ignored in the drive to meet the targets set by Government.240 Some targets have been found to be unrealistic or only achievable by skewing clinical priorities.241 For example, it has been claimed that clinicians have been required to see non-urgent patients before urgent ones in order to meet waiting list targets. This can lead to low staff morale and frustration with the ‘targeting culture’.

The DoH has recognized some of these concerns and has announced a reduction in the number of targets and focusing on ‘key outcome standards’ (eg a reduction in the number of deaths from breast cancer) rather than focusing on particular aspects of the service (eg waiting times for those needing breast screening).242

### 12 Charging: community v health care

As mentioned at the start of this chapter, one of the precepts of the NHS is that it should be free at the point of delivery. Services must be free of charge unless there is express legal provision saying they may be made.243 There is, for example, provision to require payment for wigs, drugs, and optical and dental appliances. This makes the definition of what is a service that can be expected of the NHS crucial, because if a service does not fall under the purview of the NHS, it may be subject to charging.

The area where this issue has come to a head is in respect of the distinction between community care and health care. The NHS and Community Care Act 1990 requires local authorities to prepare and publish plans for community care services in their area. Community care includes the provision of accommodation for adults who cannot look after themselves;244 services for adults who suffer certain disabilities;245 services to promote the welfare of elderly people;246 and services for those who have been discharged from mental health services.247 The kinds of services involved might include the adaptation of homes, the provision of equipment and home help etc. Under the NHS and Community Care Act 1990, section 47 local authorities are required to assess the needs

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243 NHS Act 1977, s 1(2). See Road Traffic Charges Act 1999 which permits the NHS to recover costs in relation to treatment following road traffic accidents.  
244 National Assistance Act 1948, s 21.  
245 National Assistance Act 1948, s 29.  
246 Health Services and Public Health Act 1968, s 45.  
247 Mental Health Act 1983, s 117.
of anyone who may appear to be in need of community care services and to decide
whether such services should be provided. Those who are blind, deaf, dumb, or sub-
stantially and permanently handicapped by illness, injury, or congenital disability are
entitled to be involved in the assessment process under the Disabled Persons (Services
Consultation and Representation) Act 1986 and can make representations in response
to the assessment.

It is important to realize that the NHS and Community Care Act 1990, although
conferring a right to assessment, does not guarantee that those services will be provided.
In the case of disabled clients, and those who are blind, deaf, dumb, or substantially and
permanently handicapped by illness, injury, or congenital disability there is a duty on
local authorities to provide services necessary to meet the individual's need under the
Chronically Sick and Disabled Persons Act 1970. However, for others it would be pos-
sible for the local authority to assess a person as in need of services, but then decline to
provide them. However, if that were to happen then judicial review may succeed if the
decision not to provide services is found unreasonable.

Even if the local authority decides to offer community care services, they are not free
of charge, and the local authority can require the client to pay as much of the cost of
the services as is reasonable. This means that there is often means testing in the case
of services provided at home. The distinction thus created between health care services,
which are free at the point of delivery, and community care which is not is one that is
hotly debated, not least because it is such a hard one to draw. In R v North and East
Devon HA ex p Coughlan it was decided to close a residential unit for those with
severe disabilities. This meant that Ms Coughlan, a resident, would be transferred from
the NHS to local authority services, and that meant she would be liable to contribute to
the cost of care. The key point before the Court of Appeal was that under the NHS Act
1977 all nursing care had to be provided and funded by the NHS. However the Court
of Appeal thought that nursing care in this context did not include all after-care. The
Court of Appeal identified two categories of person who should receive care at NHS
expense: (i) those whose needs were so great that they should be regarded as the respon-
sibility of the health authority, rather than the social services; and (ii) those who have
additional requirements beyond the need for basic services. Now the Health and Social
Care Act 2001, section 49 provides that nursing care cannot be charged for by a local
authority. This is defined as being care given by, or planned and supervised by, a regis-
tered nurse, unless it cannot be said to be required for a person. The section states:

(1) Nothing in the enactments relating to the provision of community care services shall
authorise or require a local authority, in or in connection with the provision of any
such services, to—

(a) provide for any person, or
(b) arrange for any person to be provided with,
    nursing care by a registered nurse.

(2) In this section ‘nursing care by a registered nurse’ means any services provided by a
registered nurse and involving—

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248 If someone is being cared for by an unpaid carer (eg a spouse) then the carer can ask the local authority,
when carrying out its assessment, to consider her or his ability to continue to provide the care.
249 Health and Social Services and Social Security Adjudications Act 1983, s 17.
250 [2000] 3 All ER 850.
Local authorities’ criteria for payment, with this section in mind, have been described as ‘confusing and unsettled’. The problems were highlighted by a series of complaints heard by the Health Service Ombudsman in 2003 and 2004. The investigation of those complaints made it clear that some disabled people were wrongly denied funding. The Ombudsman found evidence of delays and difficulties in interpreting eligibility criteria for full funding. Reviews were carried out improperly, and even where it was found that money was due to individuals there were delays in making restitution. The Ombudsman found in over half of the cases examined that assessment had not been carried out properly. Similar problems were found in the Department of Health’s own study of the issue. The Ombudsman has sought to visit each local authority to discuss improved good practice in this area.

REALITY CHECK

Confusion over payment for care

The following is a typical case dealt with by the Ombudsman.

Mrs P’s husband was diagnosed with Parkinson’s Disease in 1985 and his wife cared for him at home until early 2003 with the help of support services. However, following a stay in hospital, Mr P was discharged into a nursing home. His wife was sent a bill for his care by the PCT but she argued that, as her husband’s need was primarily for health care and he had complex needs, he should qualify for fully funded NHS continuing care. The PCT told her that Mr P did not meet the criteria for full funding but did not say how this decision had been reached. In a letter to Mrs P the PCT’s Continuing Care manager said that if Mr P had been eligible for continuing care NHS staff would have said so. However, Mr P had never been assessed for continuing care. Department of Health guidance requires that all patients needing long-term care should have a continuing care assessment before being discharged from hospital—whether to a care home or to their own home. The patient and their family should be informed about the outcome and given the opportunity to make a formal appeal. None of this happened in Mr P’s case. Instead, Mr P had been awarded the highest band of ‘free’ nursing care, a separate funding stream to cover only the nursing element for those needing care who do not meet the criteria for full continuing care funding (Registered Nursing Care Contribution, RNCC). Sadly, Mr P’s condition was terminal. A continuing care assessment was finally carried out on 9 June 2003 and the PCT then decided that he was eligible for full funding. Mr P died on 26 June 2003. Mrs P complained to the Ombudsman that she did not understand why her husband qualified for the last two weeks of his life but not for the six weeks prior to the assessment. The Ombudsman expressed concerns about the review undertaken by the PCT and the contradictory and unclear letters sent to Mrs P by the PCT. She recommended that a proper review should be carried out. This was undertaken and Mr P was found to have been eligible for full funding for the whole period.

251 Newdick (2005: 118).
252 Parliamentary and National Health Services Ombudsman (2005).
253 DoH (2004m).
Mrs P was given a full apology for the distress she had been caused, and payment to cover the whole period during which her husband had been in the nursing home.

13 Health inequalities

A major concern is inequalities in the level of health across the UK. There are notable disparities in the general quality of people’s health in different parts of the country and among different social, ethnic, and economic groups. There are also differences in the quality of NHS service offered. The following figures demonstrate this:

- One report shows that in September 2004, 7 per cent of patients in Scotland and 9 per cent of patients in England had waited for more than six months for an operation. In Wales the figure was 36 per cent.
- In some areas there are five times the number of people per GP than in others.
- The National Audit Office’s examination of cancer treatment in England found wide variation in cancer mortality rates, with higher rates in areas with highest levels of deprivation.
- Children from ‘manual work’ social backgrounds are 1.5 times as likely to die during infancy as those from ‘non-manual work’ social backgrounds.
- Those living in wealthier parts of the country can expect to live seven and eight years longer than those is less affluent areas. Glasgow had the worst life expectancy, 72.9 years, compared to Kensington and Chelsea in London with 82.4.
- Infant mortality rates in the poorest parts of the country were 19 per cent higher than the general population. The rate of infant deaths is 70 per cent higher in the West Midlands than in the South East.
- A Health Care Commission Report found that some groups got ‘a worse deal’ from healthcare services than others, especially travellers, homeless people, those with learning difficulties, and those who live in poorer parts of the community.

The Government states it is determined to reduce these inequalities. Specifically it has a target to reduce inequalities in the levels of infant mortality and life expectancy by 2010.

14 Choice

‘Choice’ has become one of the ‘buzz words’ of the modern NHS. The emphasis on choice has been seen by many as an emphasis on consumerism within the NHS. It reflects what might be seen as a shift from seeing the patient as the ‘recipient’ of care, to
treated her or him as a consumer who chooses what services she or he wants. Supporters argue that increased choice will lead to increased satisfaction as individuals get the treatment they really want, and improved quality of services as health care providers vie to be the providers of choice for patients.

The Government has clearly emphasized the importance of choice in its NHS Improvement plan:

Patients’ desire for high-quality personalized care will drive the new system. Giving people greater personal choice will give them control over these issues, allowing patients to call the shots about the time and place of their care, and empowering them to personalize their care to ensure the quality and convenience that they want.269

The plan was that by the end of 2005 patients would have the right to choose from four or five different health care providers; and from 2008 they have the right to choose from any provider. Under the new computer system patients will have access to their own ‘Health space’ where they can note individual preferences about their care.270 There is to be increased access to information to enable ‘shared decision-making between patient and clinical team over treatment and care’.271 We are moving towards a ‘patient-led NHS’.272

Some of this may frighten some patients. They want to go to the doctor and be told what treatment is best for them and for the doctor to make the necessary arrangements. To be involved in ‘shared decision-making’ may not be what they want at all. Others, maybe those with access to the internet and other health care resources, will have strong views on how they want their health problems to be dealt with and will find the new approach liberating.

At first giving patients choice may appear to be an inevitable good, but this is not beyond dispute.273 Providing a choice will cost money and that raises the question about its cost-effectiveness. Also, offering a choice means we must accept that on occasion the wrong choice will be made. It might also be argued that it is a little misleading to talk about choice when, given rationing within the NHS, the choices of an individual patient must be weighed against the interests of the general public. Can we really allow patients to choose treatments under the NHS which are not cost-effective? Will that not amount to a waste of previous NHS resources? Surely we cannot let one patient’s choice mean another is denied treatment they need? There are also concerns that choice empowers the educated middle class, who are in a better position to make ‘choices’ and to insist that their wishes are met; and conversely disadvantages weaker members of society, who are not in a position to make a choice, or do not have the voice to insist upon it. Exercising choice may require having the means to travel to a hospital far from one’s home, and this may not be possible for those with low incomes. Indeed if a majority of people in an area with a struggling hospital choose to go elsewhere for treatment, this may lead to the closing of the hospital and the restriction of choice for those less able to travel. These arguments may not mean that choice should not be a relevant goal for the NHS, but that respecting choice can carry expenses and dangers, and steps may need to be taken to limit them.

270 DoH (2004f: 12).
272 DoH (2005a).
273 King’s Fund (2003b).
15 Regulation by professional or NHS bodies

It is not possible to provide a complete guide to the regulatory work done in the nature of regulation by professional or NHS bodies. These bodies have all reviewed their regulation of professionals particularly following the Bristol Inquiry. There it was said: ‘We cannot say that the external system for assuring and monitoring the quality of care was inadequate. There was, in truth, no such system’. It will only be possible to highlight the work done by a sample of bodies:

15.1 The Department of Health

The Department of Health will discipline those involved in professional or personal misconduct. NHS Trusts will be responsible for disciplinary investigations and proceedings involving members of their staff.

15.2 The National Patient Safety Agency

This is a special health authority which has responsibility for co-ordinating efforts to learn from adverse events and ‘near misses’. It collects data on these and finds information from other countries and other industries. It seeks to ensure that the lessons that can be learned are learned and that practical steps are put in place to ensure that risks are eliminated or diminished.

This authority assists local NHS bodies to deal with ‘performance problems’. These are concerns about the outcomes of cases in which particular medical professionals have been involved. It promotes local and national procedures which are aimed at preventing, identifying, and resolving ‘performance problems’. It also provides advice in assisting individual doctors and dentists to improve their practice. The Agency may refer cases to the GMC or other professional body where there are serious concerns.

15.3 The General Medical Council (GMC)

Although we shall look at the GMC, this is by way of an example; there are similar bodies with similar powers over a range of medical professionals. Section 1A of the Medical Act 1983 states the primary role of the GMC:

The main objective of the General Council in exercising their functions is to protect, promote and maintain the safety of the public.

As we shall see there have been claims that it is the interests of doctors rather than the public which has dominated the concerns of the GMC. The GMC has the job of keeping a register of medical practitioners. In fact the law on this is rather lax. It is not an offence to practise medicine if you are not registered, indeed you do not even have to be qualified. However, if you falsely represent yourself as being a qualified or registered

274 See Glynne and Gomez (2005).
275 Bristol Royal Infirmary Inquiry (2001: 8).
276 DoH (2005g).
277 This work used to be done by the National Clinical Assessment Authority, which is now part of the National Patient Safety Agency.
278 Medical Act 1983.
279 Brazier and Cave (2007: 6).
doctor then an offence is committed under the Medical Act 1983. It is likely that the courts will find that a person who sets themselves up as a doctor is impliedly representing themselves to be qualified. However, if someone is open about being unqualified (eg they claim to be an alternative health practitioner) then people are free to trust their care to them and no offence is committed.

The GMC, as already indicated, has come under fire in recent years, particularly following three enquiries which highlighted the problems over the GMC’s supervision of the medical profession:

- **The Shipman Inquiry.** This will be discussed in Chapter 8. The fifth report of the Shipman Inquiry observes how complaints procedures could have prevented Dr Shipman from killing. The inquiry held that the GMC was not to blame for the events. It was proposed that a new database be created to store all the known information about doctors, including records of disciplinary action by employers, information held by the GMC, and the Criminal Records Bureau.

- **The Ayling Inquiry.** In 2000 a GP, Clifford Ayling, from Folkestone was convicted on 12 counts of indecent assault on women patients. The GMC removed him from the Medical Register. Dame Anna Pauffley chaired a public inquiry into the case. Despite complaints raised by patients it had taken a long time for an effective response—there appeared a widespread reluctance to believe that the complaints could be true.

- **The Neale Inquiry.** Richard Neale, a former gynaecologist, was erased from the Medical Register in July 2000 for poor standards of care. Although the GMC had been notified of action taken by Canadian Authorities, the GMC took no action in response to concerns over this doctor. The GMC admitted to the inquiry that this was ‘extraordinary and inexplicable’.

In response to these cases the GMC has created a new procedure which is as follows: when a complaint is received it will be investigated by two case examiners: one medical and one lay. This is intended to enable a rapid response to concerns. If they are unable to agree, the Investigation Committee of the GMC will consider the complaint. If the investigators decide there is a need to act quickly to protect the public, then the case can be referred to an Interim Orders Panel who can take action pending a full hearing. When the investigation is complete a Fitness to Practice Panel will conduct a full hearing. The Panel will contain independent panellists who will be specially trained. The Panel can prevent a doctor from practising medicine or place restrictions on the kind of work she or he does. The doctor can be erased from the medical register, meaning that she or he will be excluded from the medical profession. Only in exceptional circumstances will an excluded doctor be restored to the register. A doctor can be suspended so that she or he cannot practice for the period of the suspension. A warning can be issued where there is a significant departure from good medical practice, but not such as to warrant removal from the register. The Panel must provide reasons for its decision. A doctor can appeal to the High Court. The Council for the Regulation of Healthcare Professionals can appeal against a decision which it regards as imposing too lenient a punishment.

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280 The deception may be sufficient to negate consent to any procedure and therefore render it an assault (*R v Tabassum* [2000] 1 Rep Med 404).


The GMC is also taking pro-active measures to try to highlight doctors who may pose a risk to patients. They will be asking all doctors to give details about their practice. If they are not in an ‘approved environment’ (eg the supervision of their work is very limited) the GMC will take further steps to ensure there is monitoring of what they do.\(^{283}\) The GMC will also do much more to ensure there is effective sharing of information between the NHS and other employers about concerns over professionals.

Complaints made to the GMC have increased almost 15-fold, since 1990.\(^{284}\) This increase suggests a growing willingness to lodge a complaint against doctors and may be interpreted as indicating decreasing deference to the medical profession. This may also suggest that there are inadequacies in the informal complaints process.

A report by the Chief Medical Officer\(^{285}\) recently recommended substantial reform to the current system of professional regulation. It was noted that once a doctor achieved independent practice there was never formal assessment of their competence, while an airline pilot might expect to be assessed about 100 times during their career. Further, the report noted that the GMC was too secretive and ‘too tolerant of sub-standard practice’.\(^{286}\) The report accepted that part of the problem with the current climate is that:

A culture of blame and retribution has dominated the approach to this whole field so that it has been difficult to draw a distinction between genuine misconduct, individual failure, human error provoked by weak systems, and untoward outcomes which were not the result of any specific failure. An ‘off with their heads’ approach to every problem will ultimately make healthcare and medical practice more dangerous, since no one will admit their own mistakes, nor will they want to condemn a colleague’s career to ruin.\(^{287}\)

However, the report concluded that the GMC (and equivalent professional bodies) should retain their functioning of regulating conduct. It recommended significant reforms to the way complaints are dealt with and hearings conducted.

A report issued by the Department of Health\(^{288}\) recommended that an independent body carry out adjudications of whether a doctor was fit to practice. This set out the principles which should govern the regulation of medical professionals:

- First, the body’s overriding interest should be the safety and quality of the care that patients receive from health professionals.
- Second, professional regulation needs to sustain the confidence of both the public and healthcare professions through demonstrable impartiality. Regulators need to be independent of Government, the professionals themselves, employers, educators, and all the other interest groups involved in health care.
- Third, professional regulation should be as much about sustaining, improving, and assuring the professional standards of the overwhelming majority of health professionals, as it is about identifying and addressing poor practice or bad behaviour.
- Fourth, professional regulation should not create unnecessary burdens, but be proportionate to the risks it addresses and the benefits it brings.
- Finally, a system is needed that ensures the strength and integrity of health professionals within the UK, but is sufficiently flexible to work effectively for the different

health needs and health care approaches within and outwith the NHS, and to adapt to future changes.

A central proposed change is that regulatory councils have a majority of members who are not members of the profession and that their members are appointed independently. The aim of this measure is to avoid perceptions of bias that are currently all too prevalent. There are also proposals that all doctors will need to re-licence and can do so only having shown they are fit to continue practicing.

QUESTIONS

1. ‘To the seventy-six-year old woman with liver failure, we must say: “For all your children and grandchildren, we can’t spend this much on you.” To the patient with one heart transplant: “I’m sorry but we can’t afford to give you more than one heart because it costs too much and because another person awaits the next heart”. To life long smokers: “Sorry, no lung transplants. You could have stopped smoking”. Do you think, as Pence (2002: 110) indicates in this quotation, that we need to be more blunt about rationing? If we do, do you agree with his comments?

2. Having read this chapter do you think we need to spend more on the NHS? What do you think of Belshaw’s (2005: 48) point: ‘Hardly anyone thinks that we should put all our money into the health service, and none at all into pizzas, or holidays, or schools.’?

3. What role should age take in rationing decisions? In an ICM Poll carried out for NICE, people were asked on a scale of one to ten ‘How important do you think the age of the patient should be when deciding what treatments can be given on the NHS’; there was no consensus. But when asked ‘If extra money became available for the NHS, how would you prioritise where the money should go? Young children? People of working age? People over the age of 65?’ the responses were 45 per cent for children, 19 per cent for those of working age, and 12 per cent for people over 65.

4. Do you think that it can never be right to give someone a multiple organ donation (ie a donation of two organs at the same time)? The argument being that the two organs could have saved the lives of two people and so should never be used to save just one (Menzel (1994)).

5. If you were allowed to create your own rationing system for your own health care what things would you want and not want to receive treatment for?

6. Porter (1997: 718) wrote: ‘It is endemic to a system in which an expanding medical establishment faced with a healthier population, is driven to medicalizing normal events like menopause, converting risks into diseases, and treating trivial complaints with fancy procedures. Doctors and “consumers” are becoming locked within a fantasy that everyone has something wrong with them, everyone and everything can be cured.’

Do you agree?

7. In 2005 a nurse was told by her health authority that it did not offer Herceptin, a drug to treat breast cancer. After great media interest and the intervention of the Department of Health, the health authority said that it now regarded her case as exceptional and that she would receive the drug (BBC Newsonline, 3 October 2005). Is it right for politicians to intervene in cases like this?
FURTHER READING

On rationing generally see:


On the work of NICE see:


Harris, J. (2005c) ‘It’s not NICE to discriminate’ *Journal of Medical Ethics* 31: 373.


On Oregon see:


On public health see:

On rights under EU law see:

On professional and government regulation see: